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Together for Change: Investigating a Socio-technical System Approach for Supporting Miscarriage

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Abstract

Globally, miscarriage is affecting a substantial number of women: about 1 in 5 women who know they are pregnant miscarry. Importantly, miscarriage can be profoundly distressing, and lack of social support during and after a miscarriage can greatly affect women's wellbeing. Unfortunately, miscarriage is not a commonly discussed topic, despite the significant number of miscarriages occurring. As a result of the lack of discussion around the subject of miscarriage, it continues to be stigmatised and misunderstood. Consequently, there is inadequate communication between women who have experienced miscarriage and care networks when communicating their social support needs.

This thesis investigates how technology can be meaningfully leveraged to enhance those communications. As a theoretical framework, the thesis author uses the Circles of Care Model, which has previously successfully been used to understand the complex context of caring for people with chronic illness. The research process was strongly participatory, inspired by principles of Community-Based Participatory Research. The main contributions of this thesis are: (a) an in-depth and rich holistic contextual understanding of the social support needs of women who have miscarried, describing in-depth their practices and use of technology (b) extending the Circles of Care Model approach to designing a socio-technical system for miscarriage care (c) proposing empirical design goals for socio-technical systems for miscarriage care that are grounded in mixed methods research with women from different cultures and different health care systems.

In collaboration with ProHealth Lab, University of Indiana, Bloomington, United States, we began with an exploratory Asynchronous Remote Communities (ARC) study to investigate the breadth of miscarriage experiences, the support needs that arise, the people who can help, and the potential scope for technology to facilitate the support needed. The study involved 16 activities (discussions, creative tasks, and surveys) posted in two closed, secret Facebook groups over eight weeks. Women who have miscarried face barriers to receiving appropriate social support when communicating with their care network. Since miscarriage still carries a considerable stigma, women hear unwanted responses and belittlement of the loss, which made them more hesitant to reach out. They often felt unable to discuss their feelings and thoughts openly, as they feared a lack of empathy. Without having a guiding hand, women who have miscarried feel alone in this experience. They live experience that no one has prepared

them to, very few people understand and sometimes is challenging to get support. This left many overwhelmed with complex social support needs while in a raw emotional state, and often with insufficient informational, emotional, esteem and network support at the time. While women experiencing a miscarriage utilise various technology channels for seeking support when other options fail them, each woman only focuses on a few online streams. We developed the Miscarriage Circle of Care Model (MCCM) to mapping the formal, informal care networks, and their respective roles in providing social support. Our findings highlight the importance of integrating the Peer Advisor support to provide holistic support for a woman experiencing a miscarriage.

Next, the thesis author carried out five sets of 1:1 co-design workshops with women who have miscarried to investigate how technology might help address their unmet support needs, given the map of formal and informal care networks we developed. The workshops were structured around a journey mapping exercise. The thesis author also used card sorting to explore mental models of miscarriage support. The thesis author collected data both from women who had miscarried and those who had not experienced miscarriage themselves but felt a strong connection to the topic. We involve women who have not experience a miscarriage in the process to explore the different clustering behaviour between women with experience of miscarriage and those without experience, which in turn, help to understand how the experience of miscarriage changes the perception of support. The thesis author distilled the findings into actionable design goals, which were then instantiated in a wireframe prototype of the socio-technical system solution, which was designed to be able to fit into a pregnancy app. The thesis author evaluated the prototype in another five series of 1:1 workshops using techniques from usability testing, such as task analysis, and methods from service design, such as love letters / break up letters. Overall, women considered the prototype to be useful and acceptable, with suggestions for improvements.

The thesis author concludes with a critical reflection of the process and findings and provides a conclusive description and suggestions for implementing them in practice. Through reflection on the experiences in conducting research for this thesis, including the difficulties we faced and decisions we made, we derive insights into the role of design, power relations in the community and research in a sensitive area. We conclude with a discussion of limitations and discuss how the MCCM developed in this thesis might be implemented within existing miscarriage care in the United States and United Kingdom healthcare systems.

Lay Summary

Miscarriage is the most common complication in the early stage of pregnancy. Importantly, women suffer from both physical and psychological problems after the miscarriage. However, women who have miscarried are unhappy with the received information and support from friends, family, and healthcare providers after the loss. This research looking at information and support needs of women during and after the event of miscarriage with the aim of designing a technology solution to provide accessible social support for women who are experiencing and have experienced miscarriage.

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Declaration

I declare that this thesis was composed by myself, that the work contained herein is my own except where explicitly stated otherwise in the text, and that this work has not been submitted for any other degree or professional qualification except as specified.

(Mona Alqassim)

*To unfortunate people
who have lost a child
due to miscarriage...*

It was not you when you threw, but it was Allah Who threw it, that He might cause the believers to successfully pass through this test.

Surah Al-Anfal Verse 17, Holy Qur'an

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“ I learned to think. Then, I learned to think inside the boxes. Then, I realised that the right way of thinking is by breaking the models and think outside the box. “

Rumi

1

Introduction

The number of people who have experienced miscarriage is substantial. Globally, it is estimated that about 1 in 5 pregnancies (15-20%) ends in miscarriage [Edwards et al., 2016, Prior et al., 2017]. Recurrent miscarriage, a consecutive pregnancy loss that has occurred three or more times, affects one percent of couples [Prior et al., 2017]. Although miscarriage is an unpredictable event, those who have miscarried often view it as a personal failure. They may blame and punish themselves and cite their lifestyle and habits as a cause [Puddifoot and Johnson, 1997]. Up to five percent of women who have miscarried experience post-traumatic stress symptoms [Gergett and Gillen, 2014]. The loss can trigger anxiety and depression [Rowlands and Lee, 2010], anger, and the urge to self-harm [Gergett and Gillen, 2014]. Women may grieve deeply for years after miscarriage [Lok and Neugebauer, 2007], and the grief reaction can be as intense as that related to perinatal death [Johnson and Langford, 2010].

Despite the significant number of miscarriages occurring for women in the UK and around the world [Edwards et al., 2016, Prior et al., 2017], miscarriage is not a commonly discussed topic [Geller et al., 2010]. As a result, miscarriage continues to be

stigmatised and misunderstood [Andalibi and Forte, 2018], and the communication between women who have miscarried and their formal care network (e.g., health care providers), and informal care network (e.g., family members) is often difficult [Evans et al., 2002, Wong et al., 2003, Abboud and Liamputtong, 2005, Séjourné et al., 2010]. Appropriate social support for women who have experienced miscarriage can provide a much needed boost to their wellbeing, both in the short and long term [Gergett and Gillen, 2014]. The provision of social support for women who have miscarried is often inconsistent or insufficient [Baird et al., 2018]. For example, while informal care networks understand that miscarriage is a difficult event to experience, they believe that relief can be found by replacing negative emotions by more positive ones [Maker and Ogden, 2003]. The formal care network usually give priority to the physical wellbeing of the women with psychological needs not given the same priority [Séjourné et al., 2010, Gergett and Gillen, 2014].

However, the more satisfied women are with the level of social support received, the less likely they are to experience mental health issues following miscarriage [Séjourné et al., 2016]. Therefore, although women who have experienced miscarriage need to gain support, for example, by talking to their care network about miscarriage, they are often unable to express any emotion relating to their loss and wish their care network to be more sensitive to their situation [Rowlands and Lee, 2010, Meaney et al., 2017].

Medication, lifestyle changes, and "watchful waiting" with medical monitoring are among traditional techniques for supporting miscarriage [Empson et al., 2005, Devaseelan and Regan, 2010, Wahabi et al., 2018]. Hospital, community-based care improvements, and sensitive after-care services have the potential to enhance women's wellbeing after miscarriage [Stratton and Lloyd, 2008, Rowlands and Lee, 2010]. Providing tangible assistance, counselling, psychotherapy and supportive listening can decrease symptoms of depression and grief after pregnancy loss [Neugebauer et al., 2007, Swanson et al., 2009]. In-person support groups have also proven successful during and after pregnancy loss [Côté-Arsenault and Freije, 2004]. Although the beneficial outcomes of these interventions have been recognised [Swanson et al., 2009, Côté-Arsenault and Freije, 2004], only a small percentage of those who have miscarried actually receive psychological treatment [Betts et al., 2014]. Hence, the lack of social support is often not adequately addressed [Geller, 2012, Betts et al., 2014], which is a major risk factor for emotional wellbeing after miscarriage [Bellhouse et al., 2018a].

More recent attention has focused on the technological provision of services based

on the internet, to help women cope well after experiencing pregnancy loss. These services have valuable features, such as constant accessibility and anonymous disclosure [Geller, 2012]. Examples include psychotherapeutic intervention, providing access to information, and providing access to support groups, which provide an opportunity for obtaining emotional support and for self-expression [Kersting et al., 2011, Séjourné et al., 2016]. Women who had experienced miscarriage used internet discussion forums to seek support that they were not receiving from the healthcare providers [Betts et al., 2014]. The potential anonymity of online platforms such as Facebook and one-to-many disclosure makes women feel comfortable to use these platforms to disclose the loss [Andalibi and Forte, 2018]. Psychotherapy-based solutions are more oriented towards formal care network provision, while studies of online forums emphasise the informal care network [Kersting et al., 2011, Séjourné et al., 2016, Betts et al., 2014, Andalibi and Forte, 2018].

Given the impact of appropriate social support and the care networks' communications pattern on women's wellbeing, as well as alternative forms of technology service delivery [Kersting et al., 2011, Séjourné et al., 2016, Betts et al., 2014, Andalibi and Forte, 2018], we propose to consider the role that digital technology could play in helping care networks to support women who have miscarried and the communication between women and their care network. Technology can be used as a medium for support in a way that is suitable for supporting miscarriage services, care networks and women who have miscarried. However, we argue that useful and usable socio-technical systems need to take into account the context in which women go through the miscarriage experience, which includes the social support needs, the availability of people in the care networks, and women's use of and access to technology. Therefore, where existing research aims to address the medical needs of women who have miscarried (e.g., [Lok and Neugebauer, 2007]) or understand the psychological impact of miscarriage (e.g., [Van Den Berg et al., 2014]), in this thesis, we consider the social experiences in common and the potential of socio-technical systems to support these experiences.

A socio-technical system (STS) is a system that considers requirements spanning both the technical aspect of organisation and the social aspect of society and people, which then leads to systems that are more acceptable to end-users and deliver better value to organisations [Baxter and Sommerville, 2010].

The Circle of Care Model (CCM) is an approach to the structural modelling of care

networks [Price, 2010]. It places the person who receives support and care at the centre of their own “Circle of Care”. Those who give care, be it formal or informal, are then linked to the person in the centre by their role [Kitson et al., 2013, Price, 2016]. CCM has been successfully used to model healthcare organisation and coordination across complex networks involving continuity of care [Price, 2010, Price and Lau, 2013], personal health records and patients’ medication communication [Kitson et al., 2013]. A CCM provides a structured, patient-centric view of care provision that can be used to design better services [Price, 2016]. We discuss CCM in more detail in Chapter 2, Section 2.4.3.

1.1 Research Aim and Questions

In this thesis, we design a prototype for a technological service that can address women’s unmet social support needs, and that goes beyond a discussion forum or a peer networking app. We view this service as a STS that should be designed in a way that is accessible and acceptable for women who have miscarried and promotes their communication with care networks. To this end, we investigated the following research questions:

[RQ1] What are the experiences of women who have miscarried?

c.f. Chapter 3.

- Who are the key people in the care network of women who have miscarried?
- What are the social support needs of women who have experienced miscarriage, and to what extent are these support needs being met?
- How could technology provide opportunities to improve social support communications?

[RQ2] How might we support the experience of women with miscarriage through design?

c.f. Chapters 4, 5, and 6.

- How do women who have miscarried communicate with their care network?
- How can we leverage technology to increase social support and make existing social support easier to access?
- How should technology be designed to align to the Circle of Care Model ?

[RQ3] How might we facilitate social support among women who experience miscarriage and their care network?

c.f. Chapter 7.

- What form of intervention might help the experience of women who have miscarried and could this support be provided through a socio-technical system?
- How do we design a socio-technical system which supports women in a sensitive manner?

[RQ4] How can involving women who have miscarried in the research process inform future healthcare models to support miscarriage?

c.f. Chapter 8.

1.2 Overview of Thesis Research and Approach

This research aims to understand how technology can play a role in supporting the social support needs of women who have miscarried. Women who have experienced miscarriage are the intended end-users of the STS, and they need to be involved with opportunities for expressing their needs and perspectives in the process of research, as well as the design of these support provisions. To do this, we adopted many principles of Community-Based Participatory Research (CBPR). CBPR is a research approach where the community members (as the clients or intended users) and researchers are equitably collaborating and involved in all stages of the research process, from defining the problem to translating the results into action, instead of just being studied [Connell et al., 1995, Seifer and Connors, 2000]. Those principles include understanding the existing strength and resources within the community, finding opportunities for mutual learning, and disseminating that knowledge to all partners. This CBPR approach has been shown to be effective when working with participants to develop other context-sensitive technology interventions [Weiss and Lorenzi, 2008, Hunsberger et al., 2014, Bartlett, 2015]. We present more details about CBPR approach in Chapter 2, Section 2.5.

Because miscarriage is a relatively new area of study in socio-technical research, in a collaboration with the Proactive Health Lab (ProHealth), University of Indiana, Bloomington, United States, we began with an exploratory quantitative and qualitative study with women who have experienced at least one miscarriage, using the Asyn-

chronous Remote Communities (ARC) method *in Chapter 3*. The ARC method is a useful group-based method for engaging with people via the Internet who find it hard to attend face-to-face interviews or focus groups [MacLeod et al., 2017b, Prabhakar et al., 2017, Maestre et al., 2018b, Kresnye et al., 2019]. In a typical ARC study, participants take part in a series of moderated activities over 8–12 weeks in a closed, secret Facebook group. Activities can be private, such as completing a survey off Facebook, or public, such as discussing a post. We conducted this study to investigate the breadth of miscarriage experiences, identify people in the women’s care networks who were considered a source of different types of social support and any unmet support needs, and scope out potential technology to support the women. We found that women who have miscarried face barriers to receiving appropriate social support and encounter substantial barriers when communicating with their care network. This makes it more challenging to receive appropriate informational, emotional, esteem and network support and navigate their social support needs through various channels. Based on these findings, we used the CCM framework to develop a Miscarriage Circle of Care Model (MCCM), which maps the formal and informal care networks, and their respective roles in providing social support. In MCCM, we highlight the importance of Peer Advisor in providing holistic support for the women experiencing miscarriage.

Next, we carried out a set of five 1:1 co-design workshops using Journey Mapping methods with women who have miscarried to focus specifically on those communications between women who have miscarried and their care network and investigate how technology might be designed to help address unmet social support needs, given the MCCM mapping of formal and informal care networks we developed. We also conduct an online card sorting method involving both women who have miscarried, and those who had not experienced miscarriage themselves but felt a strong connection to the topic, to explore the different clustering behaviour between women with experience of miscarriage and those without experience, which in turn, help to understand how the experience of miscarriage changes perception of support. As a result of this exploratory work, we learned that by introducing mobile technology for providing social support, women can access the required support from their care network in a timely, safe and convenient manner. Nowadays, mobile applications have previously been identified as useful tools for improving the communication between people and their care network [Liu et al., 2011, Tang et al., 2012]. This investigation then led to distilling our findings into actionable design goals which were then instantiated in a

wireframe prototype of a mobile application solution for supporting miscarriage.

Following this, we evaluated the prototype in another five series of 1:1 workshops involving women who have miscarried using techniques from usability testing, such as task analysis, and methods from service design, such as love letters/break-up letters. We found that women who have miscarried had a shared perception towards the mobile application for supporting miscarriage concepts and the challenges surrounding integrating the system into a pregnancy system. We identified opportunities for the technological tool to enable a MCCM and provide social support for women who are experiencing or have experienced miscarriage. Empowering a MCCM leads to enhancing women's knowledge, and the knowledge of the formal and informal care network, thus enhancing the knowledge of the whole community and wider society about miscarriage.

This research has hence been built on quantitative and qualitative mixed research methods. Each study in this research has used a CBPR approach [Unertl et al., 2015] in order to design a technology to support women who have miscarried with communicating their social support needs to their informal and formal care networks. Throughout the research process, we engaged with women who have miscarried, and in one part of the research women who have not, and consulted with the Miscarriage Association (MA) as a relevant charity organisation. The MA was selected based on the organisation's ability to understand miscarriage experiences. The role and nature of the partnership with the MA throughout the research process can be outlined as following: defining the problem together; consulting them for the study design, facilitating access to resources and participant recruitment through their personal network and social media account; frequent communication and meetings held with to brief on the progress made while ensuring the trustworthiness of participants' data; and disseminating the findings of each study to gain their feedback. It is important to note that we only considered design inputs from participants and not from the MA charity partner as an organisation.

1.3 Research Contributions

This research aims to investigate how STS can be designed in a way that is accessible and acceptable to support women who have miscarried and promote their communication with care networks. This thesis makes three main contributions:

1. an in-depth and rich holistic contextual understanding of the social support needs of women who have miscarried, describing in depth their practices and use of technology.
2. extending the CCM approach to designing STS for miscarriage care.
3. proposing empirical design goals for STS for miscarriage care that are grounded in mixed methods research with women from different cultures and different health care systems.

1.4 Thesis Outline

Our work can be broadly divided into three parts. Part I details existing research significantly informing this thesis. *Chapter 2* provides a definition of miscarriage and describes the impact of miscarriage on women's well-being. Next, we review theoretical foundations of social support, situating our work within the context of prior research in the fields of STSs and HCI. We also draw upon insights from more specific explorations of traditional and digital technologies implemented to support the well-being of women who have miscarried. In addition, the chapter reviews the approaches to designing digital solution in this domain and identifies the existing gaps in the literature that this research intends to address. This review serves to define the scope of this thesis and motivate the methodological decisions made throughout this research.

Part II details the four main studies that make up this thesis. *In Chapter 3* we perform a needs assessment together with women who have miscarried at least once using the ARC method. This study was conducted collaboratively with the Prohealth lab, Indiana University, Bloomington, United States. In order to formally describe our findings, we adopt the CCM to propose a miscarriage circle of care, which outlines formal and informal care networks, and their respective roles in providing social support. Peer Advisor emerge as a particularly important part of the miscarriage circle of care. Based on our findings, we discuss and highlighting into the importance of integrating the Peer Advisor support to provide holistic support for the woman experiencing a miscarriage. We discuss the potential of technology to deliver the needed support to women who are experiencing or have experienced miscarriage, and describe how our findings informed the co-design phase.

Next, in *Chapter 4*, we introduce the co-design phase and describe a set of five co-

design workshops where we focused specifically on the interactions that participants have with their care network, the services that should be included, and how they should be delivered. Based on the analysis of the workshops, and the MCCM developed in the previous chapter, present a set of design requirements for a STS solution to support women who have miscarried.

In Chapter 5, we describe an online card sorting study which was designed to help us understand the mental model of miscarriage and miscarriage support. We recruited both women who had miscarried and those who had not experienced miscarriage themselves, but felt a strong connection to the topic. The results of this study inspired the information content of the app described in Chapter 6. We also discuss lessons learned from involving women who have not experienced miscarriage in this part of the design process.

Chapter 6 summarises the design goals that emerged from the studies and distils them into a prototype for an app, *Journey*. The key idea is to integrate support for women throughout the entire miscarriage process into a pregnancy app that is linked with their formal care network (i.e., healthcare provider) to support the women throughout the entire miscarriage process, provide them with easy, timely access to their social support, and help educate their care network.

In Chapter 7, we report the findings from a formative evaluation study of the prototype with women who have miscarried. Our goal was to understand the design considerations and underlying MCCM of such a system. We found that the prototype offers convenient services and a discreet way to help women who have miscarried access the full spectrum of social support although room for improvement remains. We conclude by articulating the outcomes of the co-design study, and providing a list of design elements required for technologies to support formal care network-integrated mobile application technology.

In Part III, which consists of *Chapter 8*, we reflect on the findings of the four studies in the context of our research questions and discuss how they might be implemented in practice. In particular, we discuss how our work on the MCCM might be expanded to cover miscarriage service provision in a particular health care system. In particular, we discuss the US and UK healthcare systems, since most of the participants in our studies had experienced these two systems. We then reflect on our experiences in conducting research for this thesis, discussing the difficulties we faced, decisions made, and the

resulting limitations. We present insights into the role of design, power relations in the community and research in a sensitive area within the methodological design process. Finally, we conclude this thesis by discussing opportunities for extending this work into future directions and research.

Notes

The study described *in Chapter 3* was conducted in collaboration with Cassie Kresnye, Katie Siek (ProHealth Lab at the University of Indiana) and Maria Wolters. This study has two strands of data collection, the thesis author focused on social support and technology usage, while the Indiana team focused on miscarriage timelines and information needs. While the ARC is collaborative, the thesis author have responsibility for one half and Cassie have the responsibility for the other. The thesis author, Cassie Kresnye, Katie Siek, and Maria Wolters designed the study. The thesis author and Cassie Kresnye were responsible for data collection, and we shared the data once was collected. The thesis author led the analysis for data related to this thesis.

Ethical approval for this study was granted by the Institutional Review Board (IRB) (Reference Number: 1709149336) of Indiana University, and the Psychology Research Ethics Committee (PREC) (Reference Number: 209-1718/1) of the University of Edinburgh. Indiana University acted as the formal sponsor. The study was the basis for publications [[Alqassim et al., 2019](#), [Kresnye et al., 2019](#)]

The studies described in *Chapters 4, 5, and 7* was conducted by the thesis author. Those studies were approved by the PREC, University of Edinburgh (Reference Number: 298-1819/7), and was sponsored by the University of Edinburgh. They are as yet unpublished.

*“United we stand, divided
we fall “*

Aesop

2

Background

2.1 Introduction

In this chapter, we provide an overview of the existing work that most significantly influenced this thesis. The purpose of the first section is to describe background information on miscarriage. We describe what is meant by miscarriage, how it is defined, and outline the impact of miscarriage on women’s wellbeing. In the second section, we review existing research on social support, beginning with theoretical foundations. We draw from work in social psychology to understand different types of social support and support communications. Understanding these types of social support allows us to examine to what extent the social support needs of women who have miscarried are met or unmet. In our research study, we are interested in the women’s formal care network (healthcare providers) and informal care network (e.g., partner, family, friends) as a source of support and we aim to identify areas where support is lacking. We also provide a foundation from which to explore the social support needs and the nature of the communication between women who have miscarried and their care networks. This assists our understanding of the barriers to providing or seeking social support.

Understanding how those norms vary through communication helps to contextualise the differences in sources of different types of support.

In the third section of the chapter, we sample related work from the health and other socio-technical fields that address known challenges with social support for miscarriage. In this section, we discuss how social support interventions to support miscarriage are managed by the care network with or without digital means, together with the strengths and weaknesses of these interventions. The aim here is to provide an understanding of existing efforts to digitally support women who have experienced miscarriage. We conclude this section by drawing from previous work suggesting a shift towards the Circle of Care Model (CCM), which we propose as a valuable lens for thinking about supporting women who have miscarried. The last section of this chapter serves to motivate our research approach throughout the thesis; we discuss the influence of this background of miscarriage on our methodological choices. We conclude by drawing upon insights taken from the findings from each of these sections to design spaces for new innovative socio-technical systems for women who have miscarried with regard to this thesis.

2.2 Miscarriage

2.2.1 Defining Miscarriage

Miscarriage, also known as Early Pregnancy Loss [Obstetricians and Gynecologists, 2015], has been defined in varying ways throughout the data sources used in this study. In earlier literature, it usually meant an intrauterine pregnancy ending unintentionally in a loss before 28 weeks [Cuisinier et al., 1993, Everett, 1997], while in the more recent literature it refers to pregnancy loss that occurs before 20 weeks' gestation or at foetal weight less than 500 g [MacWilliams et al., 2016, Olson, 2013]. There are several reasons for these varying definitions of miscarriage, such as diagnostic uncertainties and moral or legal difficulties in some countries [Hemminki, 1998]. Recurrent miscarriage is a consecutive pregnancy loss that has occurred three or more times and affects one percent of couples [Rai and Regan, 2006, Prior et al., 2017]. Miscarriage usually happens in the first trimester [Ventura et al., 2012] and only one percent happen after 12 weeks' gestation [Prior et al., 2017]. Regardless of the foetus' gestational age, a miscarriage is a traumatic event and highly emotional time for a woman and the people close to her [Nikcevic et al., 2000, Van, 2001, Abboud and Liamputtong, 2005, Ney

et al., 1994]. Extensive research since the 1990s shows that miscarriage has remained the most frequently reported form of reproductive loss [Miron and Chapman, 1994, Paton et al., 1999, Abboud and Liamputtong, 2005, Hammerslough, 1992, Andersen et al., 2000, Lok and Neugebauer, 2007]. It is well established that about one in five pregnancies (15–20%) end in miscarriage [Hammerslough, 1992, Beutel et al., 1995, Andersen et al., 2000, Paton et al., 1999, Everett, 1997, Ventura et al., 2012, Edwards et al., 2016, Baird et al., 2018]. Although miscarriage is common, it received less attention in earlier medical literature than other pregnancy complications [Hemminki, 1998, Lok and Neugebauer, 2007].

2.2.2 Miscarriage and Women's Wellness

A large and growing body of literature has investigated the physical and psychological effects of miscarriage on the health of the women concerned. Abboud and Liamputtong [2005] state that while miscarriage is not a serious health condition, it does threaten a woman's emotional and physical health, as well as her social relationship. Several succession studies indicate that feelings of anger, guilt, prolonged grief, lowered self-esteem, depression, post-traumatic stress or anxiety disorders are common, not just following the miscarriage [Engelhard et al., 2001, Klier et al., 2002, Geller et al., 2004, Neugebauer and Ritsher, 2005, Gold et al., 2012, Lok and Neugebauer, 2007, Brier, 2008b, Mann et al., 2008, Blackmore et al., 2011, Medjedović Marcinko et al., 2011, Séjourné et al., 2016] but also during the subsequent pregnancy [Frache and Mikail, 1999, Geller et al., 2004, Serrano and Lima, 2006, Van Den Berg et al., 2014].

2.2.2.1 Grief

As early as 1984, research conducted by Leppert and Pahlka explored and confirmed the extent and the nature of the grieving process in women who experience miscarriage [Leppert and Pahlka, 1984, Lasker and Toedter, 1991, Neugebauer et al., 1992a, Puddifoot and Johnson, 1997]. Generally, grief can be characterised as "pathological grief"; that is, a person may find it difficult to cope with daily life activities and interaction with other people [J. Toedter, 2001]. The grief reaction after miscarriage can develop into pathological grief and it can take 3–4 months to resolve grief symptoms [Lok and Neugebauer, 2007]. However, others state that the grieving process may take up to 1 or 2 years, particularly in the case of pathological grief [Leppert and Pahlka, 1984, Lin and Lasker, 1996, Beutel et al., 1995, Janssen et al., 1997].

Moreover, the grief following miscarriage can be as intense as that due to perinatal death [Puddifoot and Johnson, 1997, Johnson and Langford, 2010, Baird et al., 2018].

2.2.2.2 Depression and Anxiety

Since the early 80s, there has been an awareness of the importance of the emotional well-being of women following miscarriage [Peppers and Knapp, 1980, Lovell, 1983, Herz, 1984, Cecil, 1994]. Women who have miscarried can experienced anxiety, depression, anger and the urge to self-harm [Brier, 2008a, Gergett and Gillen, 2014]. Moreover, the miscarriage may trigger mental health problems, including clinical levels of anxiety and depression [Cumming et al., 2007, Rowlands and Lee, 2010]. Additionally, not only may depression occur after miscarriage [Friedman and Gath, 1989, Neugebauer et al., 1992b] but symptoms of anxiety and depression can be present for as long as 6 months afterwards [Neugebauer et al., 1992b, Kim and Graeme, Geller et al., 2004].

2.2.2.3 Stress

Various research studies have observed the increased levels of stress after miscarriage [Day and Hooks, 1987, Ptettyman et al., 1993]. Lee and Slade [1996] point out that experiencing miscarriage can be a traumatic event and is usually accompanied by emotional distress. Also, up to 5% of women who had miscarried experienced post-traumatic stress symptoms [Gergett and Gillen, 2014]. Although miscarriage is an unpredictable event, women who have miscarried view this event as a personal failure; they may blame and punish themselves and cite their personal practice and habits as a cause [Herz, 1984, Puddifoot and Johnson, 1997, DeFrain et al., 1996, Dunn et al., 1991].

In this research, we were looking at the experience that women who have miscarried have in common, regardless of when the pregnancy was lost and to what extend the loss affect their wellbeing. The commonality of miscarriage is at the crux of this research which aims to help address this widespread problem, rather than focusing on specific and well-defined type of loss.

2.3 Social Support

In this section, we review existing research on social support, beginning with theoretical foundations. We draw from work in social psychology to understand different types of social support and how we define them.

2.3.1 Defining Social Support

Different definitions exist in the literature regarding the meaning of social support. [Albrecht and Adelman \[1987\]](#) defined social support as “verbal and nonverbal communication between recipients and providers that reduces uncertainty about the situation, the self, the other, or the relationships, and functions to enhance a perception of personal control in one’s experience” [[Albrecht and Adelman, 1987](#), p. 19]. Further, [Cohen et al. \[2000\]](#) defined social support as “the social resources that persons perceive to be available or that are actually provided to them by non-professionals in the context of both formal support groups and informal helping relationships” [[Cohen et al., 2000](#), p. 4]. Although social support has been broadly defined by researchers, there is a consensus over its definition as providing a person in need with beneficial interaction and a helpful attitude [[Rook and Dooley, 1985](#)]. Social support is most effective when it matches the needs and preferences of the people who require it, and is perceived by them to be helpful [[Shumaker and Brownell, 1984](#), [Cutrona and Russell, 1990](#)]. Many researchers have attempted to identify types of social support; however, recognised social support research covers the following five different types: informational; emotional; network; esteem; and tangible [[Cobb, 1978](#), [Kahn, 1979](#), [Schaefer et al., 1981](#), [Weiss, 1974](#)]. [Cutrona and Russell \[1990\]](#) divide these five social support types into two main categories: action-facilitating support and nurturant support. For this thesis, we rely on the taxonomy of [Cutrona and Russell \[1990\]](#) to understand different types of social support because of its suitability for surveying social support measures in the previous literature on offline social support [[Coursaris and Liu, 2009](#)], and computer mediated communication for social support [[MacLeod et al., 2017a](#), [Maestre et al., 2018a](#)].

2.3.1.1 Action-Facilitating Support

The first category of social support is **Action-facilitating** support, which is intended to eliminate or actively solve the problems faced by the person who needs support. It

Table 2.1: [Cutrona and Russell \[1990\]](#)' definitions of the five categories of social support.

Action Facilitating Support	Informational Support	<i>"advice ('I think you should tell your supervisor'); factual input ('If you don't treat the infection quickly, it will get worse'); and feedback on actions ('You shouldn't have told her so bluntly')."</i>
	Tangible Support	<i>"offers to provide needed goods (e.g., money, food, books) and services (e.g., baby-sitting, transportation, housework)."</i>
Nurturant Support	Emotional Support	<i>"expressions of caring ('I love you'), concern ('Are you feeling better?'), empathy ('You must have been really hurt by his coldness'), and sympathy ('I'm so sorry you're upset')."</i>
	Esteem Support	<i>"expressions of regard for one's skills, abilities ('I know you'll do a good job') and intrinsic value ('Losing your job doesn't mean you're worthless')."</i>
	Network Support	<i>"a sense of belonging among people with similar interests and concerns ('We'd like you to join our support group')."</i>

involves informational and tangible support [[Cutrona and Russell, 1990](#)].

Informational support is intended to help a person to manage or solve a problem by providing guidance, advice, or facts [[Feng and MacGeorge, 2010](#), [Rains et al., 2015](#)]. People who give informational support provide knowledge regarding a particular situation or issue to reduce uncertainty [[Hether et al., 2016](#), [Coursaris and Liu, 2009](#)]. They may also offer ideas or advice, suggest actions, refer to another source of information or teach by explaining facts, news, and the skills needed for the recipient to deal with the situation facing them [[Hether et al., 2016](#), [Wang et al., 2017](#), [Coursaris and Liu, 2009](#)]. This type of support also involves helping to appraise the situation by reassessing or redefining it [[Hether et al., 2016](#), [Coursaris and Liu, 2009](#)] and it gives examples of personal experience of a health condition [[Wang et al., 2017](#)].

Tangible support, also known as instrumental support, involves offering physical aid and financial assistance [[Krause, 2009a](#), [Coursaris and Liu, 2009](#), [Rains et al., 2015](#), [Hether et al., 2016](#)]. It may include lending recipients things, including money, or di-

rectly performing tasks for them [Hether et al., 2016, Coursaris and Liu, 2009]. This type of support may also include giving gifts, including money [Hether et al., 2016], and indirectly performing tasks [Coursaris and Liu, 2009]. Tangible support also consists of offering assistance with grocery shopping, household chores, gardening and personal care as well as transportation [Wang et al., 2017, Gaveras et al., 2014, Krause, 2009b].

2.3.1.2 Nurturant Support

The second category of social support is **Nurturant** support, which is intended to provide consolation and comfort without actively solving the problem or facilitating action. It involves emotional, esteem and network support [Cutrona and Russell, 1990].

Emotional support expresses empathy and affection for the recipients and supports their own emotional expression [Rains et al., 2015, Burleson, 2003, Hether et al., 2016]. It focuses on emotional feedback, understanding and feeling, rather than information [Hether et al., 2016]. People who provide emotional support typically reflect on personal experience to show sorrow to the recipient and empathy of the situation. Emotional support also focuses on providing encouragement with confidence, hope and sometimes prayer for the recipients [Hether et al., 2016, Wang et al., 2017]. It is also about providing affirmation, concern, validation and care [Wang et al., 2017]. Emotional support also includes relationship support centring on love and closeness [Coursaris and Liu, 2009] as well as confidentiality, defined as “promises to keep the recipient’s problem in confidence” [Braithwaite et al., 1999].

Although *Esteem support* is distinguished from emotional support because it concentrates on a person’s self-perceptions rather than their emotions [Hether et al., 2016], it has been considered as a specific type of emotional support that aims to enhance how a person feels about their accomplishments and abilities [Holmstrom, 2012]. Esteem support focuses on validation by expressing agreement with the recipient’s perspective of a situation, including the recipient’s beliefs, actions, thoughts or emotions. Esteem support also focuses on relief from blame by alleviating the recipient’s feelings of guilt about the situation, as well as compliments by saying positive things about the recipient [Coursaris and Liu, 2009, Hether et al., 2016]. However, Wang et al. [2017] identify validation as a type of emotional support.

Network support is reinforcing or expanding a person’s social connections with other

persons or groups, and thereby engendering a sense of belonging [Rains et al., 2015, Hether et al., 2016]. It focuses on friendship, which explicitly requests or offers participation in a group [Hether et al., 2016]. Network support aims also to provide the recipient with access to a new network or groups, where she is able to meet other people locally. Such groups or networks serve to remind the recipient that there are others who have had similar experiences who are available to talk and offer support [Coursaris and Liu, 2009, Hether et al., 2016]. Other studies state that network support itself is known as companionship support, and it includes humour, chatting, teasing and discussions of offline activities and daily life that may not be related to the person's health issues, such as sharing jokes and holiday plans [Wang et al., 2017].

Understanding these types of social support allows us to examine to what extent the social support needs of women who have miscarried are met or unmet. The thesis author found that women who have miscarried were devastated with complex social support needs while in a raw emotional state, and often with limited informational and nurturant support at the time. More details were discussed in Chapter 3 Section 3.3.2, and Chapter 4 Section 4.3.

2.3.2 Care Network, Social Support Seeking, and Stigma

Social support might be provided through *Formal* and *Informal* care networks. Formal networks include professional service providers, such as doctors, obstetricians, midwives and therapists, who are professionally trained and paid for their work. The informal care network involves those who are in a social relationship with the person who receives care and who are not paid for their work, such as family, friends and communities [Küçükoğlu and Çelebioğlu, 2013, Lehto-Järnstedt et al., 2004, Koffman et al., 2012, Andersson and Monin, 2018, Broese van Groenou and De Boer, 2016].

Miscarriage not only impacts the wellbeing of women who have miscarried, but their social communications and relationships [Andalibi and Forte, 2018] as well. Since the late '80s, women who have had a miscarriage have consistently reported unsatisfactory responses from their formal and informal care networks [Day and Hooks, 1987, Friedman and Gath, 1989, Kim and Graeme, Evans et al., 2002, Wong et al., 2003, Abboud and Liamputtong, 2005, Séjourné et al., 2010]. Many recent studies [Magee et al., 2003, Simmons et al., 2006, Betts et al., 2014, Séjourné et al., 2016] have shown that there are large numbers of women who require significant professional care and social support. It has been reported that the levels of grief, anxiety and depression are

correlated with the women's level of satisfaction with their couple relationship and the lack of support they receive from their informal and formal care network [Swanson et al., 2003, Lok and Neugebauer, 2007, Séjourné et al., 2016]. Maker and Ogden [2003] found that informal care networks (e.g., family and friends) understand that miscarriage is experienced as a difficult event, but believe that it can be resolved by the relief of negative emotions and by these being replaced by more positive ones. A recent study was conducted by Meaney et al. [2017] to explore the experiences of women and their partners who have experienced miscarriage. They found that the participants were unable to express any emotion relating to their loss and they wished that the hospital administration had been more sensitive to their situation. In another study, the formal care network themselves admitted that they gave priority to the physical wellbeing of the woman and that psychological needs were not given the same priority [Gergett and Gillen, 2014]. A recent study from the United States by Baird et al. [2018] aimed to better understand the overall miscarriage experience. These researchers found that many of the participating women reported complete confusion and a failure to provide information and emotional support; only a few of them felt they were informed and supported. Many reported that they left the Emergency Room (ER) with a lot of confusion and fear, with an unclear idea of what to expect next and the majority of participants had not been seen for follow-up care.

Miscarriage can be traumatising, socially stigmatised, isolating, associated with negative feelings and depression, and difficult to disclose to others [Baglia and Silverman, 2014]. Moreover, lack of support from care networks can contribute to a sense of stigma and may increase risk of depression in the wake of a miscarriage [Stinson et al., 1992b]. Women who have experienced miscarriage gain support from talking to people around them, but they are often unable to discuss their feelings [Rowlands and Lee, 2010]; especially given that miscarriage still carries considerable stigma and people often do not talk about it [Stinson et al., 1992a, Baglia and Silverman, 2014]. Therefore, women who experience miscarriage choose whether, how, and to whom they talk and communicate [Andalibi and Forte, 2018]. Consequently, the limited communication with care networks might reduce the social support that they can provide to improve the wellbeing of women who have miscarried. Care networks thus play a critical role in promoting the wellbeing of women who have experienced miscarriage by providing appropriate social support on this very sensitive and emotional journey. The care networks' roles are essential because the extension of social support needs to be pro-

vided as soon as the women experience the miscarriage. For example, within standard medical care, women who discuss their miscarriage while attending follow-up appointments are less likely to suffer from mental health problems than those without this opportunity [Jackman et al., 1991]. The potential for improved well-being through access to social support makes miscarriage a productive context on designing socio-technical systems for support seeking. Because miscarriage is common yet perceived as rare, women frequently experience social support gaps throughout their miscarriages. There are studies contribute important knowledge about people experience shame and guilt—feelings associated with miscarriage [Leon, 1992] and emotional disclosure often is restrained [Rimé, 2009].

This research has shown that women who have miscarried often receive well-meaning but unhelpful comments from their care network; especially given the miscarriage is not commonly discussed topic, it is understandable that it would be a challenging experience to understand without having gone through it oneself. However, among the strategies that have been shown in this research to be helpful are allowing the women to talk openly about their feelings and encouraging contact with people who have experienced a similar situation.

2.4 Interventions for Supporting Miscarriage

2.4.1 Traditional Interventions

There are some existing traditional interventions such as medication, lifestyle changes and the “watching waiting” approach with medical monitoring. However, these interventions fail to support the miscarriage experience [Aleman and Bergel, 2005, Empson et al., 2005, Devaseelan and Regan, 2010, Wahabi et al., 2018]. Therefore, both Stratton and Lloyd [2008] and Rowlands and Lee [2010] propose that hospital, community-based care improvements and sensitive after-care services could definitely enhance positive mental health for women after miscarriage. Further, other interventions have been developed to assist those women during the mourning and grief process. These interventions include providing practical assistance, counselling, psychotherapy and supportive listening [Neugebauer et al., 2007, Swanson et al., 2009]. In-person support groups have also been shown to be successful during and after pregnancy loss [Côté-Arsenault and Freije, 2004]. While it has been confirmed that these interventions decrease the depressive and grief symptoms after pregnancy loss, only a small percent-

age of those affected receive traditional forms of psychological treatment [Betts et al., 2014]. Hence, the lack of social support is often not adequately addressed which is a major risk factor for emotional wellbeing.

2.4.2 Technology-based Interventions

Kersting et al. [2011] introduced an internet-based psychotherapy programme to help women cope after experiencing pregnancy loss. This intervention provided a treatment in the form of written disclosure and Cognitive Behavioural Therapy (CBT) for a period of five weeks. They found that the levels of grief and post-traumatic symptoms and other negative mental health scores decreased immediately after the treatment. However, depression symptoms did not decrease until the three-month follow-up. The researchers concluded that, while this intervention facilitated anonymised and asynchronous communication across a wide geographical distribution, the internet-based treatment needed to provide more support to patients who were suffering clinical levels of depression. Another disadvantage of this treatment is that misunderstandings may occur between the therapist and patients in the absence of spontaneous clarifications. However, this intervention at that time was the first intervention that offered the possibilities for social support and networking for women after miscarriage, with the addition of the face-to-face treatment concept. More recent attention has focused on the provision of services based on the internet, such as psychotherapeutic interventions. These internet-based services provide information and support groups, and emotional and self-expression [Séjourné et al., 2016].

Betts et al. [2014] investigated the miscarriage experience and the practice of posting to internet discussion forums and they found that women who had experienced miscarriage used internet discussion forums to seek support that they were not receiving from the healthcare providers. In a more recent study, Andalibi and Forte [2018] conducted semi-structured interviews with 27 women in the US who had experienced pregnancy loss to understand the lived experiences of those who had experienced pregnancy loss and the perceived role of existing social technologies during that time. They investigated particularly the practice of seeking support through pregnancy-loss self-disclosure and discussions on social media sites such as Facebook. They found that the online platforms' anonymity and one-to-many disclosure made these platforms comfortable places to disclose the loss on Facebook. They introduced the "network-level reciprocal disclosure" (NLRD) concept, which is defined as when an individual

is motivated to disclose within his or her network, once observing others' disclosures. These findings motivated the researchers, as social computing system designers, to enhance and facilitate such social support exchange, particularly within the network level. Therefore, the interviews directly informed the requirements and the experimental prototype designs. Building on this work, [Andalibi et al. \[2018\]](#) designed a prototype mobile application “not alone”, which embodies the NLRD concept. NLRD informed their design, using the pregnancy loss context. This app aimed to better assist people who had experienced stigma and distressing events by enabling social support and disclosure with others who had undergone the same experience.

Although the beneficial outcomes of a few solutions have been proposed to offer advantages, such as constant accessibility and anonymous disclosure to support women who have experienced a miscarriage (e.g., internet-based psychotherapy program) [[Kersting et al., 2011](#)], online forums [[Betts et al., 2014](#)] and communication with their care network, these solutions, by necessity, focus on particular aspects of support provision. Psychotherapy-based solutions are more oriented towards formal care network provision, while studies of online forums emphasise the informal care network [[Kersting et al., 2011](#), [Betts et al., 2014](#)]. Therefore, in this research, we aim to discuss the role of technology in providing social support for women who have miscarried from a more holistic perspective that integrates formal and informal care networks.

2.4.3 Shifting Towards Circle of Care Model

The Circle of Care Model (CCM) is a recent approach and was first developed as a requested method for exploring the care for end-of-life patients [[Price, 2016](#)]. Circles of Care have been successfully used to model healthcare organisation and coordination across complex networks that involve continuity of care [[Price, 2010](#), [Price and Lau, 2013](#)], personal health records and a patient's medication communication [[Kitson et al., 2013](#)]. It places the person who receives support and care at the centre of their own “Circle of Care”. Those who give care, be it formal or informal, are then linked to the person in the centre by their role [[Kitson et al., 2013](#), [Price, 2016](#)]. A CCM provides a structured, patient-centric view of care provision that can be used in discussions with stakeholders to design better services. The model covers four elements [[Price, 2010](#)], which are related to each other through a patient and their needs:

1. the *person*,

2. the people who are involved in that person's care (*providers*),
3. the *communication* between network members (person and providers),
4. the *information repositories* that store information about that person.

The Circle of Care contains providers involved in a person's care. Providers in the circle of care could include both formal and informal care networks [Price, 2010]. Formal care networks comprise those who are professionally trained and have a defined, paid role, such as obstetricians, midwives and therapist. Informal care providers are those involved in a social relationship with the person who receives care, such as family, friends and communities; although they do not have a defined paid role, they could play an important, informal role within a person's circle of care [Küçüköğlu and Çelebioğlu, 2013, Lehto-Järnstedt et al., 2004, Koffman et al., 2012, Andersson and Monin, 2018, Broese van Groenou and De Boer, 2016]. Communication between providers, and between providers and a person, is also important in the circle of care as gaps in communication can lead to adverse events [Kripalani et al., 2007]. The circle of care also includes information repositories, which contain information related to a person and can be accessed by more than one provider. Patient information repositories have been seen to shift from paper to electronic systems and from departmental records to regional systems [Haux, 2006].

In this research, following recent work on modelling care [Kitson et al., 2013, Price, 2016], we recognise that CCM is an approach to the structural modelling of care networks. While information repositories element could support the linking of people in the circle of care so that information related to the person can potentially be accessed by more than one provider, this is not the focus of this research. Instead, in this research, we focus on clarifying roles and communication links between the women who have miscarried and the formal and informal care network providers who are involved in caring for the women during and after miscarriage. Shifting towards CCM rather than relying as heavily on specific care network has the potential to improve the quality of support provided, to reduce the stigma surrounding the miscarriage and activate the secondary benefits of engaging the community.

2.5 Applying CBPR to Information System Research

This section serves to motivate our research approach throughout the thesis, and the influence of this background of miscarriage on our methodological choices.

2.5.1 Action Research

Action Research (AR) is an applied research approach that has been used since the mid-twentieth century in medical and social science and has been used since the end of the 1990s in the field of Information Systems (IS). The fundamental idea of AR is that the actions of “doing and intervention” and research, “knowing and learning”, cannot be separated [Hayes, 2011]. It is a process where research is done to enable action, and learning occurs through action. The fundamental principle of AR is to introduce changes into a complex social situation and observe and understand the effects of these changes [Baskerville, 1999]. Although AR contains several subsets and terms, such as participatory research, participatory action research and community-based participatory research, the aim of all forms of action research is to carry out specific action(s) for social change [McNiff and Whitehead, 2006, Macdonald, 2012, Greenwood and Levin, 1998].

2.5.2 Community-Based Participatory Research (CBPR)

Community-Based Participatory Research (CBPR) is a participatory action research (PAR) approach where the community members as the clients, or intended users and researchers, are equitably collaborating and involved in all stages of the research process, from defining the problem to translating the results into action, instead of just being studied [Connell et al., 1995, Seifer and Connors, 2000]. However, the slight difference between CBPR and PAR overlapping approaches is that CBPR offers a better understanding of a specific phenomenon regarding communities and it integrates the knowledge gained with action to improve the wellbeing and health of the community members while ensuring cultural sensitivity [Dressler, 1993, Wallerstein and Duran, 2006, 2010, Kushalnagar et al., 2012]. The CBPR approach is used more in public health research [Minkler et al., 2003, Wallerstein and Duran, 2010, Kushalnagar et al., 2012], particularly for developing interventions to improve the healthcare needs of underserved communities [Rhodes et al., 2012, Trickett et al., 2001, Seligman, 2007].

Several informatics research projects have applied the CBPR approach. Examples include: exploring technology usage practices in particular communities [Carlson et al., 2006, Siek et al., 2009, Veinot et al., 2013, Nickell et al., 2014]; developing context-sensitive technology interventions [Weiss and Lorenzi, 2008, Hunsberger et al., 2014, Bartlett, 2015]; understanding a community problem using technology [Kinney et al., 2000] and studying CBPR as applied to informatics [Nam and Bishop, 2011, Vaughn et al., 2013, Chawani et al., 2014].

2.5.3 User Involvement

A number of techniques have been used to research complex problems, design effective solutions and develop innovative technology. Designing the technology process by involving the intended end-users as participants is one of the key factors for achieving technology success [Ives and Olson, 1984, Damodaran, 1996, Bano and Zowghi, 2013]. User-Centered Design (USD), Participatory Design (PD) and CBPR are all approaches that accommodate the intended end-user's needs and requirements in the development of the technology by using similar methodologies. The key differences between them are related to the level of engaging/involvement of the intended end-user, through the research stages (c.f. Figure 2.1).

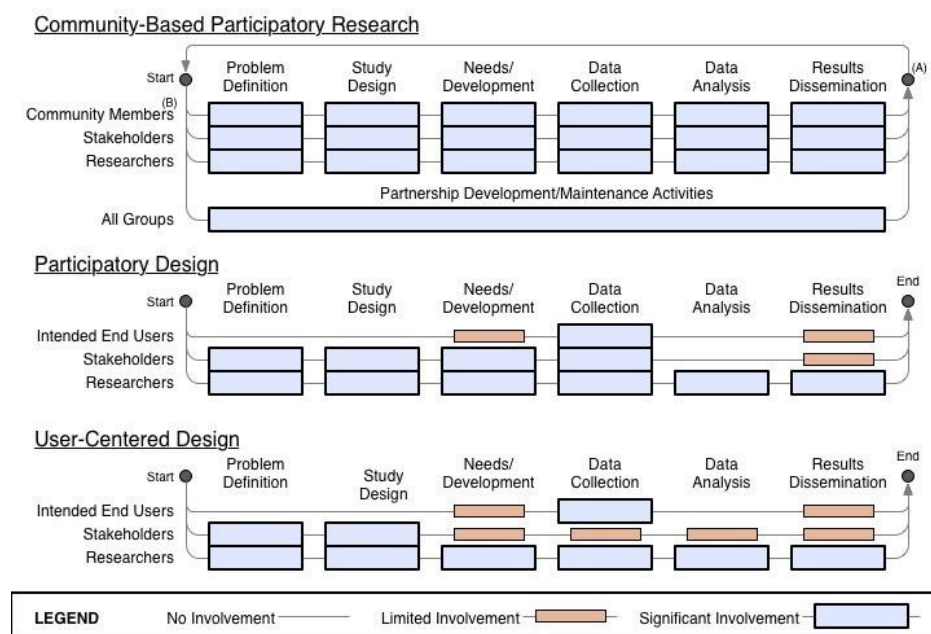


Figure 2.1: Comparison of CBPR, Participatory Design, and User-Centered Design
Adapted From Unertl et al. [2015]

In UCD, the intended users are the centre of the system design and development process, which concentrates on their needs and requirements, while researchers lead the project from study design to dissemination [Ritter et al., 2014]. However, PD empowers the intended end-user to become a collaborator and co-designer in the design and implementation process, by using specific methods and tools, while the researchers control the study design and dissemination of the results [Simonsen and Robertson, 2012]. The CBPR approach has similar concepts to the other socio-technical approaches in terms of the design and implementation of the technology, such as UCD and PD. However, CBPR comprehensively involves the intended end-user and researcher throughout all aspects of the research, while the intended end-user has limited involvement in PD and UCD research. Unertl et al. [2015] argues that the comprehensive involvement of the intended end-user, through CBPR, fundamentally alters the development of the technologies.

Moreover, community-based informatics projects often used PD and UCD methods within a broader CBPR [Arcia et al., 2013]. Particularly, the project engaged UCD in iterative development of a community-focused, socio-technical intervention, including prototyping workshops, user studies, and usability evaluations. UCD provided a structured approach for the design and development process that supplemented the CBPR framework. Other PD methods may be complementary to CBPR and deployed in unison to develop community and user-centered health interventions.

2.5.3.1 CBPR Principles

Unertl et al. [2015] extended the CBPR framework which was originally defined by Israel et al. [1998]. These revised and extended CBPR principles are used to effectively translate informatics research into practice with wider impact. These principles are briefly described in Table 2.2.

In the present research, we apply the CBPR approach as we believe that involving the community of women who have experienced miscarriage, and providing them with opportunities to express what they think, would be a way of providing more helpful support to meet their needs. Unertl et al. [2015] identified seven benefits from applying CBPR in informatics research with a health emphasis. Table 2.3 lists these benefits, with examples of the advantages of applying CBPR, particularly to this research. The nature of engagement with the organisation charity partners in our studies can be outlined as the following: facilitating access to organisation charity resources

Table 2.2: The key principles of CBPR. Adapted from [Unertl et al. \[2015\]](#).

Principles Number	Key Principles of CBPR
Principle 1	Understanding the existing strengths and resources within the community.
Principle 2	Empowering both academic and community partners through co-learning opportunities, and with awareness of social inequalities.
Principle 3	Assisting community-based organisations and community members by building and technological and research capacity.
Principle 4	Building collaborative partnership in all research phases.
Principle 5	Defining ownership of technology-related project output and planning for technology maintenance
Principle 6	Viewing research and partnership building as a cyclic and iterative process.
Principle 7	Integrating user-centered design (UCD) or Participatory Design (PD) into CBPR projects.
Principle 8	Integrating research results for mutual benefit.
Principle 9	Incorporating positive and ecological perspectives into research and technology design/deployment.
Principle 10	Disseminating knowledge to all partners through multi-modal approaches that build technical capacity and provide opportunities for additional informatics research.

Table 2.3: The benefits of applying CBPR to this research. Inspired by [Unertl et al. \[2015\]](#)

Benefits	Example
More relevant research	Research will answer questions of combined interest to the researcher as well as the community of women who have had miscarried.
Wider research impact	The community of women who have miscarried will contribute to the research and actively participate in the studies, with the acknowledgment of the importance of the topic.
Better fit between intervention and target beneficiaries	The participants will help to define the potential type of support from other angles that are different to the researcher's view on the topic, and hence result in more expressive support to their lives.
More effective recruitment and retention of diverse populations	Involving the miscarriage community members from the early aspect of the research process will facilitate the recruitment procedures, such as through linkage with community organisations and professional health providers who have closer relationships to research participants.
Improved internal validity	The engagement of the community of women who have experienced miscarriage from the early stage of the research may enhance and facilitate the data collection and analysis.
More rapid translation of research into practice	The output of this research may instantly change those women's community and lives: for example, by sharing the knowledge with the professional health care rather than only the academic research community.
Development of people	Applying this approach will give the opportunity for miscarriage community members and the researcher to learn new skills.

and participant recruitment through their community, including understanding the existing strengths and resources within the community, finding opportunities for mutual learning and disseminating knowledge to all partners.

2.6 Summary

Understanding this background of women who have experienced miscarriage informs our research in several significant ways. First, the current status of social support is inconsistent or insufficient for supporting women who have miscarried. Enhancing and improving the emotional wellbeing of these women is associated with providing appropriate social support to women who have experienced a miscarriage [Mander, 2007, Gergett and Gillen, 2014, Moulder, 2016]. Second, it means that we have a heightened responsibility to conduct research that is well-aligned with the actual social support needs and interests of women who have miscarried. Women who have experienced miscarriage are the intended end-users of the socio-technical system, and they have to be involved with opportunities for expressing their needs and perspectives in the process of the research, as well as the design of these support strategies. To do this, we rely on many CBPR principles, including understanding the existing strengths and resources within the community, finding opportunities for mutual learning and disseminating knowledge to all partners. Finally, knowing the priority of improving the social support situation for miscarriage suggests that there are issues to address that are well-suited to socio-technical research disciplines. Positive and ecological perspectives from CBPR [Unertl et al., 2015] and attitudes of designing for everyday life [Ballegaard et al., 2008] would be valuable, and thus is the focus of this research.

*“ Until you experience a miscarriage yourself,
you really don’t understand the heartbreak of
it. “*

Kathie Lee Gifford

3

Understanding Miscarriage Social Support Needs

3.1 Introduction

Researchers in socio-technical fields have sought to understand the experiences of women with a range of conditions, including pregnancy, breastfeeding, menstruation, and many others. However, miscarriage is largely new to the socio-technical and HCI research communities. Thus, we begin our research with a mixed-method (qualitative and quantitative) investigation into the social support needs and experiences of women who have undergone miscarriage. We used the Asynchronous Remote Communities (ARC) method to explore the experiences of women who have miscarried, including the physical and emotional impact of miscarriage on their wellbeing, to better understand those experiences. In this chapter, we explore people in their formal and informal care network in more depth. We outline the differences in the communications participants have with their care network. Further, we identify unmet support needs, and begin to consider possible new sources for this support. This chapter describe the method

and results of this exploratory study with women who have experienced miscarriage.

Specifically, this chapter answers the first research question listed in Chapter 1, Section 1.1. The first research question is:

[RQ1] What are the experiences of women who have miscarried?

- Who are the key people in the care network of women who have miscarried?
- What are the social support needs of women who have experienced miscarriage, and to what extent are these support needs being met?
- How could technologies address the opportunities afforded to improve social support communications?

This study has two strands of data collection, and was conducted collaboratively with Cassie Kresnye, Katie Siek (ProHealth Lab at University of Indiana) and Maria Wolters; the use of “we” in this chapter refers to those researchers. Indiana team was interested to explore the physical and emotional timeline of pregnancy loss that the designs of socio-technical system need to be aligned to deliver information. While the ARC is collaborative, the thesis author have responsibility for one half and Cassie have the responsibility for the other, and we share the data once was collected. This chapter includes materials from our CHI paper [Alqassim et al., 2019].

3.2 Method

In this study, we used the ARC method to engage with women who have experienced miscarriage. The ARC method was designed to allow participants to meet in person, regardless of location or availability, and to mitigate perceived stigma [MacLeod et al., 2017b, Prabhakar et al., 2017, Maestre et al., 2018b, Kresnye et al., 2019]. The method has been used successfully with pregnant women and new mothers [Prabhakar et al., 2017].

In an ARC study, participants engage in a series of moderated activities over several weeks in private Facebook groups, which are set to be secret so that they cannot be found by others, and private so that they can only be accessed by invitation. These activities may include surveys, free text responses, or uploading images. Each research question is typically covered by several activities, which can then be used to triangulate findings [Heale and Forbes, 2013].

ARC was chosen because it has several advantages:

1. it provides a forum where women who have experienced miscarriage can become familiar with each other over time, thereby facilitating disclosure [Andalibi and Forte, 2018];
2. it allows us to bring together women from different locations and time zones, and allows an opportunity for women with time constraints to participate at any time of their choosing, which lowers barriers to participation; and
3. participants can choose whether to take part in each activity, and when to engage in an activity.

3.2.1 Recruitment

We recruited participants from two English-speaking countries with substantially different healthcare systems – the United Kingdom (UK) and the United States (US) – to increase the generalisability of results across healthcare systems. Recruitment was mainly conducted through relevant Facebook groups and personal networks in Facebook. In the UK, we also recruited via leaflets distributed with permission in libraries, charity shops and local UK miscarriage association groups.

3.2.2 Participants

A total of 66 people expressed interest in joining the study, and 44 (66%) participants completed the informed consent process. We created two separate, secret Facebook groups, one for participants who had a live birth after their last miscarriage (**Live Birth, LB**), and the other for those who did not (**No Live Birth, NoLB**). During the first few weeks of the study, two participants from the **LB** group stopped taking part in activities, one due to family issues, the other without providing a reason. A total of 42 participants completed the ARC study, and of these, 41 completed a post-study follow up survey about their well-being which also included demographic data (c.f. appendix C for demographics survey).

The demographic data is summarised in Table 3.1; 57% of participants were from the US and 43% were from the UK. Forty participants identified as women, while one participant preferred not to disclose their gender. Participants in the **LB** group were predominantly from the US ($\chi^2(1) = 30.13, p < 0.0001$), while participants in

Table 3.1: Demographics. NoLB = No Live Birth. LB= Live Birth. '**' indicated fields where multiple options could be selected, resulting in totals greater than participant count. N = number of participants (percentage of N). One participants from NoLB group chose not to complete the demographics survey

	NoLB (n=20) N (%)	LB (n=21) N (%)	Total
No Data	1 (5)	0 (0)	
Location			
United Kingdom	9 (45)	8 (38)	17
United States	11 (52)	13 (61)	24
Age Group			
25-29	2 (10)	3 (14)	5
30-34	6 (30)	5 (24)	11
35-39	6 (30)	9 (42)	15
40-44	3 (10)	3 (14)	6
45+	3 (15)	1 (5)	4
Ethnicity '**'			
White	14 (90)	18 (76)	32
Arab	3 (14)	1 (5)	4
Asian	1 (5)	1 (5)	2
Hispanic	1 (5)	0	1
Native American	1 (5)	0	1
Black	0	1 (5)	1
Other	1 (5)	0	1
Education			
Postgraduate	6 (30)	6 (19)	12
Graduate	6 (30)	7 (22)	13
other	8 (40)	8 (40)	16
Employment '**'			
Full time	10 (45)	10 (45)	20
Part time	4 (35)	3 (14)	7
Other	7 (35)	8 (38)	15
Self-reported Facebook log in frequency			
Daily	18 (90)	20 (95)	38
4-6 times per week	1 (5)	1 (5)	2
Once a week	1 (5)	0	1
Self-reported Facebook posting frequency			
Daily	1 (5)	3 (14)	4
4-6 times per week	2 (10)	2 (10)	4
2-4 times per week	2 (14)	3 (14)	5
Once a week	5 (24)	2 (10)	7
Rarely	10 (47)	11 (52)	21
Self-reported Smartphone usage frequency			
Daily	20 (100)	21 (100)	41

the **NoLB** group were balanced across locations. Since none of the participants explicitly identified as non-binary or transgender men, we will henceforth refer to the study participants as women. Most participants identified as White. In both groups, the majority of participants had a graduate or postgraduate degree, and most were in full- or part-time employment. Most participants engaged in what can be described as passive participation on Facebook. While participants logged in almost daily, two-thirds posted once a week or less. All participants had a smartphone and use it on daily basis.

3.2.3 Study Design

Once potential participants contacted us, we sent an email with a digital copy of the participant information sheet and consent form (c.f. appendix B). We asked participants to review the sheet and inquire about any questions or concerns they have. After we answered inquiries, potential participants could consent by replying to the email with a text statement including their name and the date. Once consent form was received, we sent a link to an intake survey to participants and enrolled them into the appropriate secret Facebook group.

We posted two activities in each group per week at the same time over eight weeks. The ARC study consisted of 16 activities inspired by [Prabhakar et al., 2017], as summarised in Table 3.2. These involved participants writing about their own experiences (Free Text, n=5), posting self-made drawings (Media, n=2), and completing surveys (Survey, n=6). Free-text activities involved open discussions based on a written prompt to the group discussion. Media activities involve a physical medium that the participant may create. We asked participants to use pen and paper and create a physical medium, and to post images of the resulting drawing in a group thread to spark discussion. Free Text and Media were shared in the group to allow participants to explore, and react to ideas together, by using replies comments and reactions (e.g., Loving). Lastly, we used surveys that were sent privately to each participant's email.

The initial and final activities (A1, A2 and A16) focused on study and group management. For example, we began the study with an icebreaker activity to introduce participants to each other before asking questions about their miscarriage experience. We used an open prompt of what was the participants' preferred superpower. There were 13 research activities (A3-A15), (c.f. Table 3.2). Since women were free to complete activities as they wished, completion rates ranged from 47% to 95%. The **NoLB**

Table 3.2: Activities used in study. T= Type of the Activity (FT= Free Text, S= Survey, M= Media). N= Numbers of participants who completed the activity. The activities we focus on in this research are highlighted in bold.

Week	Activity	Type	N (%)	Live Birth N (%)	No Live Birth N (%)
1	A1: Meet and Greet	FT	37 (88)	19 (90)	18 (85.7)
	A2: Facebook Availability	Poll	38 (90)	18 (85.7)	20 (95)
2	A3: Drawn Timeline	M	36 (86)	19 (90)	17 (81)
	A4: Emotional Wellbeing Scale	S	40 (95)	21 (100)	19 (90)
3	A5: Dear Abby	FT	28 (66)	15 (71)	13 (62)
	A6: Miscarriage Experience	FT	32 (76)	18 (85.7)	14 (66)
4	A7: Circle Diagram	M	22 (50)	13 (62)	9 (42.8)
	A8: Brief COPE	S	36 (88)	20 (95)	16 (76)
5	A9: Social Communication	FT	22 (52)	13 (62)	9 (42.8)
	A10: Social Support	S	35 (83)	19 (90)	16 (76)
6	A11: Coping Mechanisms	FT	25 (57)	14 (66)	11 (52)
	A12: Missing Information	FT	21 (47)	13 (62)	8 (38)
7	A13: Importance of Information	S	30 (71)	17 (81)	13 (62)
	A14: Technology Use	S	33 (79)	18 (85.7)	15 (71)
8	A15: Future Technology	S	34 (81)	19 (90)	15 (71)
	A16: Goodbye	FT	4 (10)	2 (9.5)	2 (9.5)

group was less active than the **LB** group.

At the end of the study, both groups remained open to avoid potential harm to participants by ending supportive relationships they may have formed over the course of the study. We encouraged participants to review Facebook's privacy policy, regarding how their information will continue to be used, both at the beginning and the end of the study, when data collection was completed. Participants received compensation in the form of an Amazon gift card (£35 or \$50) for their participation in the study, regardless of their level of engagement.

3.2.4 Study Activities

The six activities we focus on in this thesis are marked in grey in Table 3.2, and are related directly to identify people in the care network, social support needs and tech-

nology usage of women who have experienced miscarriage. The evidence discussed in Chapter 2 were shown that the care networks' roles are essential because the extension of social support needs to be provided as soon as the women experience the miscarriage. We, therefore, argue that it is a requirement within this thesis to identify people in the care network for women who have miscarried and better understand who considered a source of support. We designed **A7: Circle Diagram** and **A10: Social Support Survey** to identify people in the care network of women who have experienced miscarriage. Moreover, although women who have experienced miscarriage need to gain support from their care network the provision of social support for women who have miscarried is often inconsistent or insufficient. We argue that in-depth examining of social support needs of women who have miscarried will allow for a greater understanding of where those women struggle in receiving appropriate social support. As a results, we designed **A8: Brief COPE**, **A9: Social Support Communication**, **A10: Social Support Survey**, **A11: Coping Mechanisms** and **A14: Technology Usage** to better understand how women communicating their social support needs to their care networks to cope with miscarriage, and whether there is opportunities for technology to facilitate their communicating social support needs with their care network.

Below we described each of these activities that related directly to this thesis, while Appendix D contain description for the rest of the activity including the ones that related to the research of ProHealth Lab, Indiana University.

A7: Circle Diagram

Aim: This activity is designed to determine who is in a participant's care network.

Description: In **A7: Circle Diagram**, participants were asked to draw a diagram of a series of concentric circles to detail their care network when they were pregnant (before miscarriage) and after they miscarried. We asked them to place themselves at the centre, and people from formal and informal networks who were supportive in circles around the centre, with those who provided more support closer to the centre. We provide an example of woman who had a miscarriage care network (c.f. Figure 3.1). The example for the circle diagram activity was drawn by a member of the research team who had experienced miscarriage. It was designed to illustrate how the circles should be used to structure the information, which was necessary in order to ensure that answers could be analysed in a common framework. Using that visual language, several examples of relationships were given.



Figure 3.1: Figure posted in the Facebook groups for A7: Circle Diagram. This figure provided from one of the researcher who have experienced miscarriage as an example where she shows on the left her care network while she was pregnant, and to the right her care network after the miscarriage.

A8: Brief COPE

Aim: This activity is designed to determine which coping activities are used and how they learned about them.

Description: For **A8: Brief COPE**, participants completed the Brief COPE survey and provided additional free text information about physical and emotional coping strategies. In the **A8: Brief COPE**, a 28-item survey, people reported the extent to which they used 14 different coping strategies when dealing with a particular situation [Carver, 1997]. These strategies were self-distraction, active coping, denial, substance use, use of emotional support, use of tangible support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self-blame. Questions asked in this survey can be seen in Appendix E.

A9: Social Support Communication

Aim: This activity is designed to determine how participants communicate their social support needs to their care network and the information a participant shares with different portions of care network.

Description: In **A9: Social Support Communication**, we asked participants to share with the group how they communicated with and sought support from their care network. Participants were asked to share with us: (A) How knowledgeable are the people

in their care network about their needs and their partner's needs? (B) If they were giving information to their care network, what kind of information would they give? Who would they share it with?

A10: Social Support Survey

Aim: This activity is designed to understand who is in a participant's care network and whom they relied in specific social support needs.

Description: In **A10: Social Support Survey**, participants were asked to identify the people on whom they relied in specific situations, covering informational, tangible, emotional, esteem and network support situations. Questions asked in this survey can be seen in Appendix [F](#).

A11: Coping Mechanisms

Aim: This activity is designed to understand the coping mechanisms of participants.

Description: In **A11: Coping Mechanisms**, participants were asked to share proven strategies that helped them to cope with their miscarriage as well as advice from them.

A14: Technology Usage

Aim: This activity is designed to understand what platforms the participants prefer to use to access information and support technology.

Description: Finally, in the **A14: Technology Usage** survey, we asked participants about trusted sources of information (partner, family, healthcare providers, friends). Also, participants were asked which technology they currently use to communicate with others, and to seek or receive different types of social support. Questions asked in this survey can be seen in Appendix [G](#).

3.2.5 Data Triangulation

Triangulation refers to the use of different means or sources to either analyse and/or investigate a research in order to enhance confidence in the research's findings [[Heale and Forbes, 2013](#)]. We used the triangulation method for the purpose of this study. Each study activity was triangulated with at least one other to ensure validity as the following:

1. to identify people in the care network of women who have experienced miscarriage, we triangulated the findings from **A7: Circle Diagram** and **A10: Social**

Support Survey.

2. to better understand how women communicating their social support needs to their care networks to cope with miscarriage, we used data from **A8: Brief COPE**, **A9: Social Support Communication**, **A10: Social Support Survey**, **A11: Coping Mechanisms** and **A14: Technology Usage** where we asked participants about trusted sources of information (partner, family, healthcare providers, friends).
3. to explore how technologies could address the opportunities arising to improve social support communications, we used data from **A9: Social Support Communication** and data from the survey **A14: Technology Usage** together with quantitative findings and data on device and social networking account use from the **supplementary questions in the demographic survey**.

3.2.6 Data Analysis

We used R ¹ version 4.0.2 to analyse participants' demographic data and descriptive statistics, non-parametric tests of differences between groups, and statistical analysis of quantitative data from activities A7 (people's position in the care network), A10 (people in the care network), A8 (Brief COPE scale) and A14 (trusted sources of informational support).

Qualitative analysis was conducted on the free text activities A9, and A11 and the free text responses to supplementary questions in A8, A10, and A14 using a combination of content analysis and open coding. Content analysis is a structured method for coding, which focuses on describing who said what to whom, and with what effect [Pope and Mays, 2006, Grbich, 2012, Bloor and Wood, 2006].

3.2.6.1 Inter-rater reliability

The thesis author and Cassie Kresnye, a researcher from the ProHealth lab Indiana University, independently coded the data using a combination of content analysis and open coding. Top-down codes for the content analysis derived from the first research question (c.f. Chapter 1, Section 1.1), and open coding supplemented the top-down codes. Based on the initial codes, disagreements were resolved through online discussion, researchers agreed on a codebook (c.f. Table 3.3, and the data were then

¹<https://www.r-project.org/>

re-coded).

Table 3.3: Coding scheme for social support taxonomy inspired by [Hether et al. \[2016\]](#)

Support type	Examples
Informational	<i>Suggestions/ advice</i> : to suggest actions and provide guidance. <i>Referral</i> : referring to another source of information. <i>Teaching</i> : to explain facts or teach skills needed.
Emotional	<i>Empathy</i> : to feel sorrow or empathy. <i>Understanding</i> : to understand the situation of the participants.
Esteem	<i>Validation</i> : to express agreement with perspective on the situation. <i>Compliment</i> : positive comments about participants.
Network	<i>Access</i> : to provide access to peers. <i>Friendship</i> : request to make connections or offer to talk. <i>Peer</i> : to be reminded of the availability of existing peers.
Tangible	<i>Gift</i> : to give participants something. <i>Direct tasks</i> : to perform a task directly for participants.

Interrater agreement was $\kappa=0.89$ on the overall coding of each code [[Cohen, 1960](#)]. Dedoose² was used to coordinate the coding. The resulting codes for social support types were grouped and, where appropriate, mapped to relevant categories from the literature. The five social support types defined by Cutrona and Suhr [[Cutrona and Russell, 1990](#), [Cutrona and Suhr, 1992](#)] – informational, emotional, esteem, network and tangible, and the taxonomy identified by [Hether et al. \[2016\]](#) – emerged as the best match for the categories found (c.f. Table 3.3).

3.3 Findings

3.3.1 Key People in the Care Network

Figure 3.2 shows how many participants mentioned a specific type of person in the **A7: Circle Diagram**, their ring position during pregnancy, and their ring position after the miscarriage. The lower the ring, the closer the person was to the participant at that time. Both during pregnancy and after miscarriage, participants had an average

²<https://www.dedoose.com>

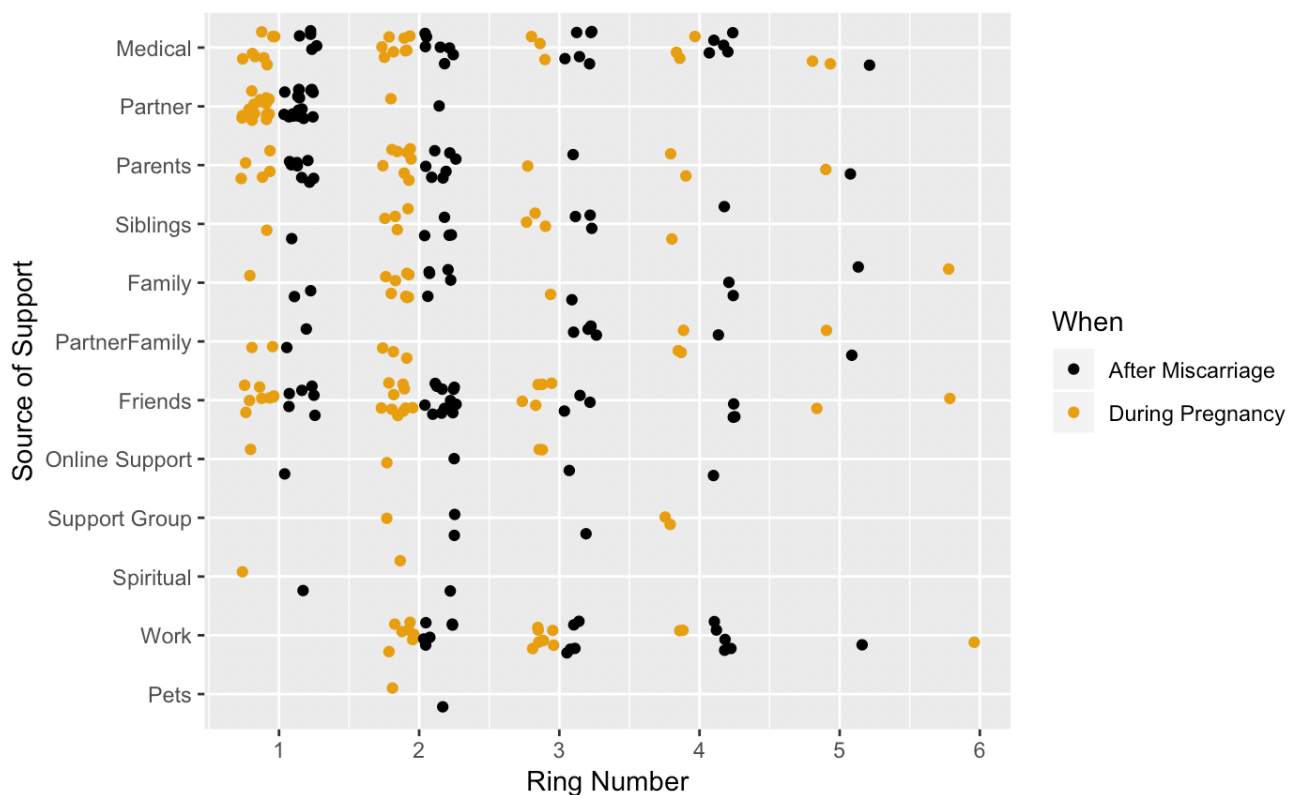


Figure 3.2: People position in participants' care network. Lower ring numbers indicate stronger and closer levels of support and involvement. 1 corresponds to the inner ring, 6 is the outermost ring specified by a participants. Positions are shown both during pregnancy and after miscarriage.

of 6 people or groups of people in all rings ($SD=3$), grouped into an average of 3 distinct rings ($SD=1$). The partner, when mentioned, was at the centre of the care network. The relative position of all other groups was far more varied. Four categories were rarely mentioned, but, when they were, tended to be seen as relatively central (ring positions 1 or 2): spiritual support; online support groups; in-person support groups; and pets. While there may have been some priming by the circle diagram example used to introduce the relevant activity, the diversity of responses suggests that participants were able to use the example and adapt the visual language illustrated with it to communicate their own situation.

When participants were asked about people to whom they could talk about anything related to miscarriage in **A10: Social Support**, Out of the 35 respondents most ($n=25$, 71%) mentioned friends, followed by partners ($n=20$, 57%). Only 40% ($n=14$) listed a person involved in reproductive care services (GP, obstetrician/gynaecologist, mid-

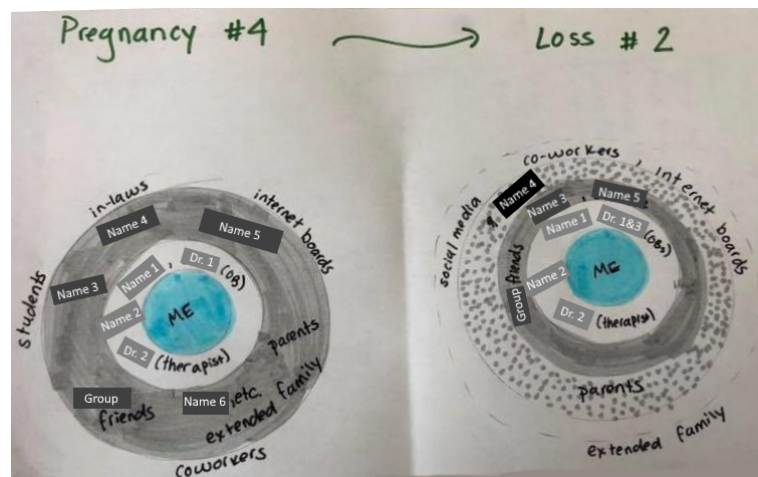


Figure 3.3: Example of generated circle diagram from activity 7

wife). Parents ($n=13$, 37%) and other family members ($n=8$, 23%) were mentioned less often. Only five people (14%) talked about online and in-person support groups.

3.3.1.1 Care Network Summary

Participants' care networks were multifaceted. Due to the large variation between individual participants, we distinguish two groups, the formal and informal care networks (c.f. Figure 3.4). The composition of the formal network varies between healthcare systems and womens' individual resources. For example, while all women had a main prenatal care provider, for those in the UK, this was the general practitioner/midwife, while for those in the US, this tended to be an obstetrician. Some women accessed doulas and therapists, while others did not mention them. Likewise, the composition of the informal network depends on womens' overall network and living situation.

3.3.2 Social Support Needs and Communication with Care Network

In this section, we begin with an overview of social support usage as a coping strategy following miscarriage. We then present in detail our findings on how participants communicate with their care network to receive and seek social support to cope with miscarriage.

In **A8: Brief COPE**, the main coping strategy identified by participants was acceptance (c.f. Table 3.4), followed by use of emotional support, self-distraction, active coping, planning, and use of tangible support. Acceptance was used significantly more

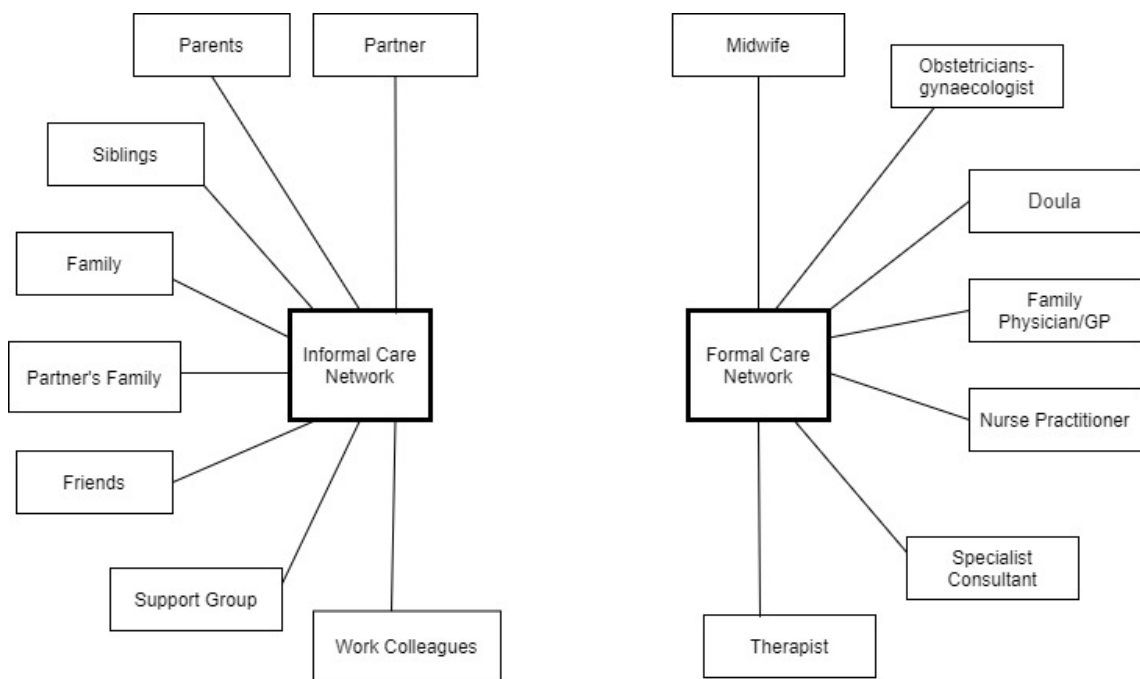


Figure 3.4: People in participants' formal and informal care networks. The main distinction is between formal and informal support. Both networks are highly multifaceted. There are no generalisable sub-groups; configurations vary by women and by health care system.

frequently than either emotional (Wilcoxon test, $Z = 2.59$, $p < 0.01$) or tangible support (Wilcoxon test, $Z = 3.29$, $p < 0.001$). The central role of acceptance as a coping strategy is illustrated by the following quotes from the free text in the supplementary section in **A8: Brief COPE** and **A11: Coping Mechanisms**.

There will always be a scar for me from these miscarriages, but I have learned to live peacefully with it. [NoLB02, A11]³.

I still coped but it was by moving forward instead of wallowing. [LB18, A8]

When discussing emotional support, participants mentioned that simply talking to someone who understood what they were going through helped them cope well with both the physical and emotional effects following miscarriage.

Talking to my friends was the thing that saved me. They heard my endless complaints and questions and supported me in my grief. [NoLB02, A11]

Tangible support, illustrated in the next quote, often involved the participant's wider

³Participants are labeled based on the group they were in (**LB** or **NoLB**), participant number, and the activity data came from (A#)

Table 3.4: Brief COPE scale. Median and Interquartile range (IQR) for No Live Birth (n=16 responses) and Live Birth (n=20 responses). Scores range from 1 (not at all) to 4 (a lot)

Coping Subscale	All Participants		No Live Birth		Live Birth	
	Median	IQR	Median	IQR	Median	IQR
Acceptance	3.5	2.5–4.0	3.2	2.5–4.0	3.5	3.0–4.0
Use of Emotional Support	3.0	2.0–3.5	2.7	2.0–3.1	3.0	2.0–3.5
Self Distraction	2.5	2.0–3.5	3.0	2.3–3.5	2.5	2.0–3.5
Active Coping	2.5	2.0–3.0	2.5	2.0–3.5	2.0	1.5–3.0
Planning	2.5	2.0–3.0	2.5	2.0–3.1	2.5	2.0–3.0
Use of Tangible Support	2.5	2.0–3.0	2.5	2.0–3.1	2.0	2.0–3.0
Venting	2.0	2.0–3.0	2.0	2.0–2.5	2.5	2.0–3.0
Religion	2.0	1.0–3.0	1.5	1.0–2.5	2.0	1.0–3.0
Self Blame	2.0	1.5–2.5	2.0	1.0–2.6	2.0	1.5–2.5
Humour	1.5	1.0–2.0	1.7	1.0–2.0	1.5	1.0–2.0
Positive Reframing	1.5	1.0–2.0	1.5	1.0–2.0	1.5	1.0–2.0
Disengagement	1.5	1.0–2.0	1.5	1.0–2.0	1.5	1.0–2.0
Denial	1.0	1.0–2.0	1.0	1.0–1.2	1.5	1.0–2.0
Use of Alcohol and other substances	1.0	1.0–2.0	1.0	1.0–2.0	1.0	1.0–1.0

network rallying around them and their partner.

My partner was amazing, and my co-workers took over my work for the week. [LB20, A8]

Although in the qualitative data, women refer to more need for emotional support than tangible support, the difference between emotional and tangible support in the Brief COPE survey scores was not significant (Wilcoxon test, $Z = 0.73$, $p < 0.47$). All other coping strategies tended to be used a little or not at all. There were no significant differences between the **LB** and **NoLB** groups regarding acceptance, use of emotional support, and use of tangible support (Wilcoxon test $Z=0.50$, $p < 0.62$, emotional support; $Z=-0.99$, $p < 0.32$, tangible support; (c.f. Table 3.4).

Moreover, other types of social support – informational, esteem and network – were also identified from the qualitative data. Participants highlighted how receiving social support through various means – whether from the healthcare provider or simply talking and reaching out to someone who understood and could validate what they were going through – also helped them to cope with miscarriage.

Finding information and I also looked to internet forums and podcasts for

more information and other people's stories. [NoLB20, A8]

I was already in therapy for other reasons when both of my miscarriages occurred, and meetings with my therapist were very important in helping me cope emotionally. I also reached out to a friend who I knew had multiple miscarriages, and she was very supportive. I also found an online chat group of women who had also experienced loss, which was helpful. [NoLB21, A8]

3.3.2.1 Informational Support

Informal Care Network

While partners were on the innermost ring of the care network in the **A7: Circle Diagram**, women trusted them only to a limited degree as a source of informational support, followed by miscarriage support groups (other people who have experienced miscarriage). Family and other types of support groups (e.g., fitness, journal club) were the least trusted sources of informational support (c.f. Figure 3.5).

Most participants reported that their informal care network members were not sufficiently knowledgeable or well-informed regarding how to provide informational support.

I also wish more medical information was readily available so our support networks can read it and they aren't relying on hearsay and the like. [LB18, A9]

Participants sought to combat this lack of knowledge and the stigma surrounding miscarriage, as it is not a commonly discussed topic, and people usually did not experience informed reactions and conversations.

My family also is not super talkative about loss, so there's that disconnect there on how to handle it. [NoLB09, A9]

Formal Care Network

The formal care network emerged as a highly trusted source of informational support in **A14: Technology Use**. The most highly trusted sources of information were formal healthcare providers (doctors, midwives), followed by doulas (c.f. Figure 3.5). The provision of appropriate informational support by a formal care network can make a substantial difference to a woman's ability to cope with miscarriage.

My new OB [obstetrician] taught me how to track fertility and helped us start thinking about options, also doing tests to make sure we ruled out any complications that might result in recurrent miscarriages. [NoLB10, A8]

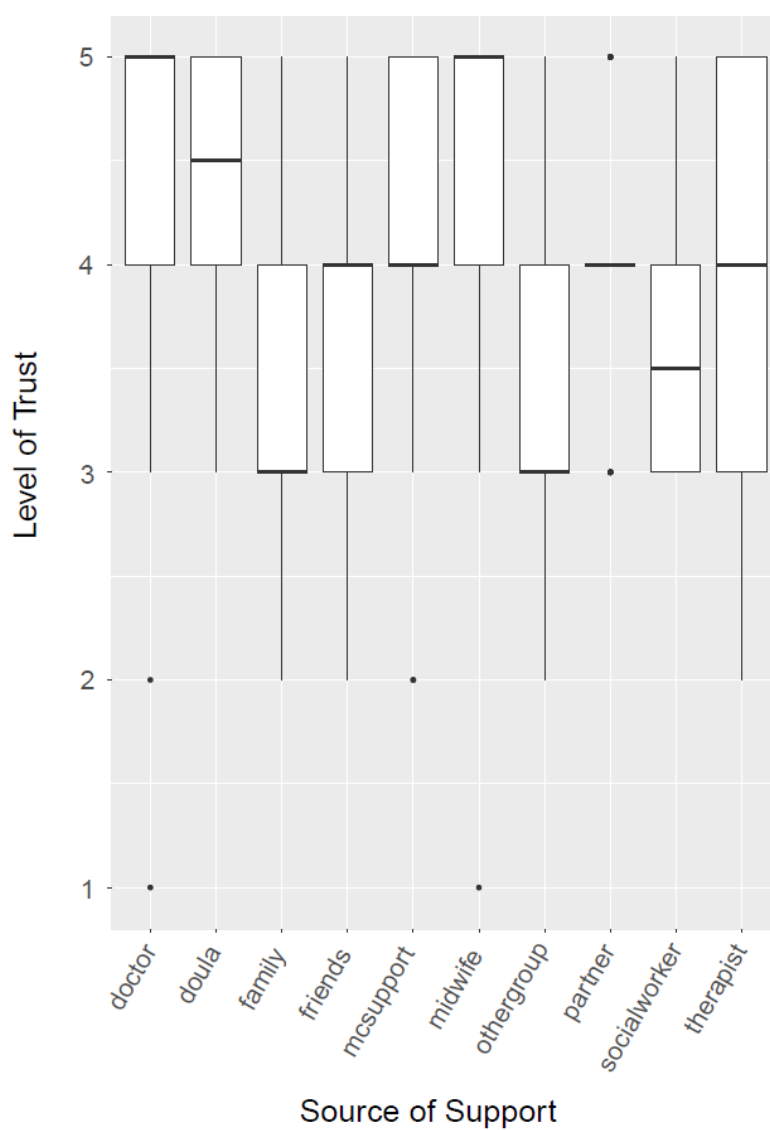


Figure 3.5: Trust levels for different sources of informational social support of both groups. 5 corresponds to "Trust Strongly" and 1 to "Distrust Strongly". mcsupport = miscarriage support group.

Eventually, I found the doctor that made such a difference with my third loss. Through my interactions with her, I was able to overcome my sadness, and feel more positive about my future; mostly because she helped me understand what steps we could take in the future to increase my odds for a successful pregnancy. [NoLB23, A8]

However, participants were vocal about a lack of informational support in dealing with miscarriage. When a formal care network fails to provide timely informational support, something they are trusted to provide, it is viewed as a sign that they do not care about their patients.

The OB [obstetrician] office and its nurses were minimally helpful in terms of [...] specific suggestions on what to do once the miscarriage starts [...]. There wasn't much guidance in terms of directions and just generally felt like they didn't care much. Whenever my husband would call the office asking for advice on how to tell how much blood loss is expected, etc., they were not helpful. [LB01, A9]

3.3.2.2 Emotional Support

Informal Care Network

Participants often described their partner as very emotionally supportive, with an understanding of the pain of miscarriage.

My husband was super supportive and understanding of allowing me space when I needed it, a shoulder to cry on, and not rushing anything. He was great through all three and was the only one to understand that just because I had gone through it before did not mean I could handle it better or that it was not a big deal. [LB06, A9]

Some participants highlighted the emotional support received from family members, while others discussed friends or co-workers playing a central role in providing empathy and sorrow.

Regarding my network, my whole family was supportive and knew my needs. [LB03, A9]

My friends have always been my real family and those who followed also every step of my pregnancies and miscarriages. Always ready to listen, patient, understanding and compassionate. [NoLB02, A9]

Participants noted that family members, friends and colleagues who had also experienced miscarriage would be very empathetic and understanding of their situation. When it was not possible to share thoughts, experiences or feelings with close people,

women with similar experiences filled the gap and were shown to provide valuable emotional support.

I do have a cousin (who is also my coworker) who has had multiple miscarriages, so we talked about it a lot together. She was very supportive and is a great resource for me. [NoLB20, A9]

On the other hand, some informal care network members expected participants to move past the traumatic and emotional miscarriage event quickly, and did not attempt to understand what participants were going through, offering up platitudes instead.

Friends and family are so full of platitudes that it is hard. I do not want to hear "it happened for a reason" or "it's God's plan", or to be told "I should be over 'it' by now". [NoLB06, A9]

Participants often felt unable to discuss their feelings and thoughts openly, as they feared a lack of empathy.

I would love to talk about anything miscarriage-related – wanting a baby, planning a baby, adoption, everything – with my family, but will not. I don't think the response would be what I need. [NoLB09, A10]

One participant theorised that people found it difficult to understand how miscarriage can be emotionally devastating, and therefore were unable to give sufficient emotional support. When we asked what they wanted to talk about with others but were uncomfortable in doing so, she said:

About the utter devastation of losing a baby. People tend not to fully understand or find it uncomfortable. [LB11, A10]

Formal Care Network

The positive experiences that participants reported show that a formal network providing appropriate emotional support can make a substantial difference to a participant's ability to cope with miscarriage in the long term.

My OB [obstetrician] also was helpful, and asked apart from medical questions also ones that concerned my psychological state. [NoLB02, A9]

Participants often reported a lack of emotional support from the front-line formal network they saw at the time of the miscarriage, which potentially made a traumatic experience even worse.

It was incredibly difficult times to get through, made worse by lack of compassion on my doctors' and their staff's part. [LB06, A9]

In fact, some participants reported that formal care network members, whom they trusted the most with regard to miscarriage-related information, often lacked empathy.

They were not always compassionate, and it was just another day and patient to them. So I guess they could do with being more knowledgeable in how to show compassion and be compassionate to those going through a miscarriage. [LB11, A9]

Participants wanted their care networks to have better understanding of their situations, and show empathy and sorrow, so that participants could discuss their feelings openly. Some participants sought to actively raise awareness of miscarriage, and to counteract the lack of understanding of their support needs, by educating their care network. Participants wanted people to realise that miscarriage is a real loss, despite it happening in the early stages of pregnancy, and that it is as hard as losing a family member or friend.

I would try to make them understand that not everyone experiences this the same way, and someone to sometimes just listen or show empathy/sympathy would be nice. [LB06, A9]

Participants were keen to raise awareness about the emotional upset and distress that they suffered after the miscarriage, and the grieving process they went through.

I wish I could teach everyone more about the grieving process: it's not neat stages, it takes a long time, it has both physical and emotional effects, and it's never something you "get over".[NoLB10, A9]

3.3.2.3 Esteem Support

Informal Care Network

A common characteristic of family members, friends and colleagues described as particularly supportive was their having also experienced a miscarriage. The shared loss created a strong network connection. Women with similar experiences provided much needed esteem support and validated participants' feelings about their experience.

A good friend had also miscarried a day after me, and maybe that also helped, as we were supporting each other. [NoLB06, A9]

My colleagues at work were great. Many of them had similar experiences, so they knew how to provide support in a helpful way. [LB16, A9]

Participants reported that their experience of loss was not acknowledged as valid by members of their informal care network, who offered unhelpful comments instead, which reflected a lack of esteem support and could be quite painful.

It would have been nicer had people said the right thing rather than “it wasn’t really a baby”. [NoLB08, A9]

Phrases like “when you have kids” are extremely hurtful. We are parents in a different way. [NoLB10, A9]

Formal Care Network

While there were some instances where participants received adequate informational and emotional support from their formal care network, when a formal care network fails to provide validation for participants’ feelings towards their loss, it is viewed as a sign that they do not care about participants’ feelings and thoughts.

We were so hurt. We were shocked by the miscarriage, but more shocked and hurt by the doctor’s response. While it may have been his umpteenth miscarriage, it was our first.[LB23, A9]

3.3.2.4 Network Support

Informal Care Network

Online and in-person support groups, as well as family members or friends who have experienced miscarriage, might represent the main sources for providing participants with network support from the informal care network.

Some extended family and some of my friends’ moms have had miscarriages and have reached out to me as well.[NoLB20, A9]

I turned to online friends more for support than anyone else – I wanted to talk to people who’d been through it, and get their tips on coping. [LB12, A11]

Support groups, where participants could meet other people who have had similar experiences, were a safe space where participants felt understood, and that engendered a sense of belonging and community that participants were sometimes unable to obtain elsewhere.

I am very fortunate to have a wonderful support group to talk to about my miscarriage.[NoLB20, A10]

Some participants proactively built their own network support, which complemented support groups organised by charities.

I also reached out to a friend who I knew had had multiple miscarriages, and she was very supportive. I also found an online chat group of women who had also experienced loss, which was helpful.[NoLB21, A8]

Support groups and other people who have miscarried were particularly important in helping participants to cope after miscarriage. However, it can take time to find them. Putting participants in touch with support groups, or with other people with similar experiences at the appropriate time was key for the healing process.

Finally, after my second miscarriage, I learned about some local in-person support resources (burial ceremony, monthly support meetings), which I am still attending through my current pregnancy, and has been one of the most important support systems for helping me cope. [NoLB21, A8]

Formal Care Network

While the formal care network was not mentioned as a source to provide network support, participants wanted their formal network to refer or signpost them to these groups as another source of support.

It would have been nice if the [HEALTH ORGANISATION] had a network to reach out and tell me about emotional support groups. [NoLB08, A9]

The RE [Reproductive Endocrinologist] was not really helpful or knowledgeable; after my first m/c, he and his staff didn't even tell me about the local support organisation. [NoLB21, A9]

3.3.2.5 Tangible Support

Informal Care Network

We explored the availability of tangible support in detail in **A10: Social Support**. Participants were asked about seven types of tangible support: cooking; laundry; cleaning; child care; driving; shopping; and pet care. None of the participants who took part in this activity were interested in pet care, but all stated that they would like help with at least one of the other activities. The median number of activities listed was three (interquartile range: 3–4), showing the relative popularity of each type of support. Cooking/meals was the most requested type of tangible support, followed by assistance with shopping, cleaning and child care.

Participants were satisfied with the tangible support received from their informal network. Most participants who stated a need for tangible support had someone in their informal care network of friends and family who could provide it (c.f. Figure 3.6).

I may ask either my mother or mother-in-law with help with cooking. Honestly, they both sent food after my miscarriage, so I don't think it would have to ask. [NoLB20, A10]

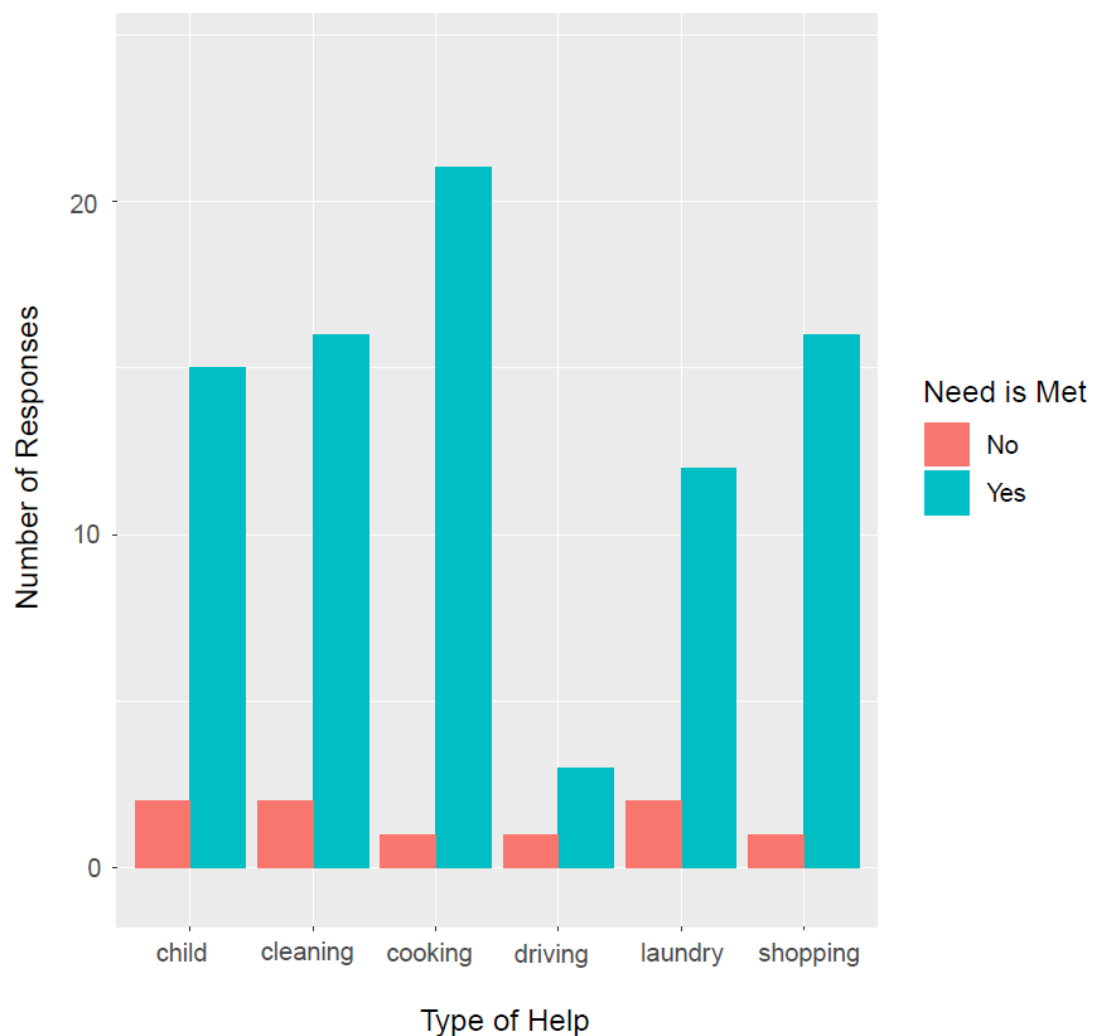


Figure 3.6: Need for tangible support. Number of responses that indicated the need for help with a chore. If the need is met, there is a person in the woman's care network who can help with the chore; if the need is not met, there is not.

While some had a wide network of helpers, others only had their partners.

My partner. We share each of [these tasks and chores], but he did it all after the miscarriage. [LB20, A10]

A few participants wanted their informal support network to be a little more proactive in reaching out to them.

I think I would want my support group to be a little more active in reaching out to provide physical help or comfort – I think they all expected I'd ask for help if I needed it, but since I didn't reach out much, they assumed I was okay. [NoLB05, A9]

3.3.3 Social Support Needs Summary

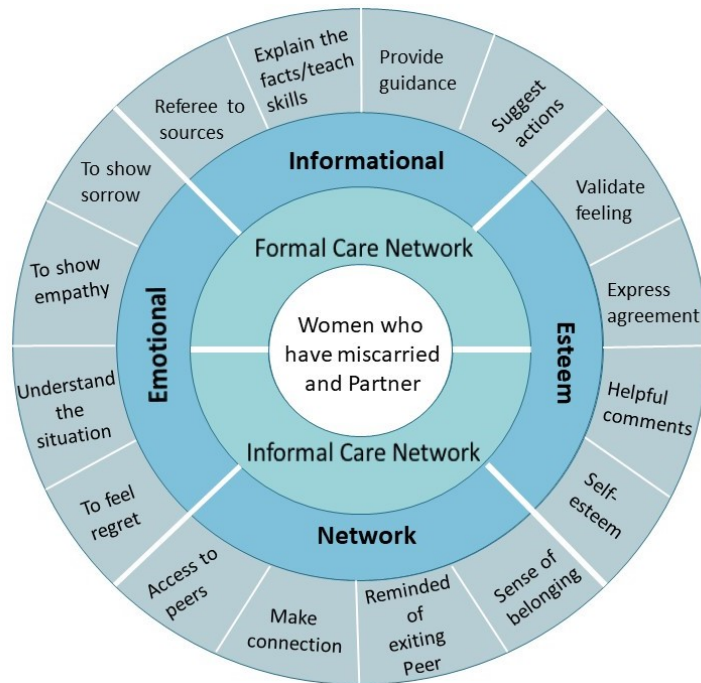


Figure 3.7: The four type of social support women who have miscarried need with several example in each type. While support cannot always be classified as needed from one resource (i.e, formal or informal care network), women who have miscarried will need support from all four areas.

When participants did receive appropriate social support, they benefited substantially. Unfortunately, sometimes, participants had to make a significant effort to find sources of social support (e.g., searching for support groups), and only found them during a later miscarriage experience. While the informal care network was mostly responsible for providing appropriate tangible support, there was substantial evidence that participants did not receive sufficient informational, emotional, esteem and network support during and after their miscarriage experience – both from their formal and informal care networks as illustrated in Figure 3.7. Due to the size and diversity of the care network, it is impossible for everyone to be perfectly supportive. However, judging by our qualitative findings, participants' care networks were often mostly composed of people who, for various reasons, were unable to provide appropriate support.

3.3.4 Technology Usage to Facilitate Coping and Social Support

We observe that if there is support needed that is not currently being provided by their formal or informal care networks, women who have miscarried turn to online resources and communities to gain support. Participants reported that this was the case for the Facebook groups and other online groups of which they were members.

I even made a Facebook post about a month after the miscarriage and received a lot of support. [NoLB20, A8]

I sought the support of my online “community” friends, many of whom had gone through similar, and it was a huge help to me. [LB12, A8]

Overall, online support groups were considered to be knowledgeable about participants’ needs and provided better comfort and support. Online networks played an essential role during womens’ grieving process and allowed women to feel less alone and gain much needed comfort.

The people in my online care network are very knowledgeable about my needs, as there are so many different friends there who have gone through all sorts. [LB12, A9]

Moreover, participants proactively sought informational and emotional support through online resources, forums and communities.

I also would ask on online forums/Facebook groups if any friends could point me at useful resources.[NoLB12, A14]

Our findings present how participants use technology and Internet forums in many different ways to remove the barriers of communication from their care network. Some participants employed the online platform to eliminate the stigma surrounding miscarriage, and notify their care network about their miscarriage. Others utilised technology to educate their care network and raise awareness of the pain of miscarriage.

I have also shared our loss on Facebook, so a lot of people will know. I think without Facebook, I would have wanted to mention the miscarriage more, so it wouldn’t feel like a secret. [No LB20, A9]

I posted information about how basically losing a pregnancy is hard, and just as hard as losing a friend or family member, and to think about the phrasing used. [NoLB06, A9]

However, it seems that social media or other internet support boards do some harm as well as good, particularly during a subsequent pregnancy and immediately following

loss.

I dropped off support groups because we are not really trying anymore ... there is no room for the narrative of 'no rainbow' and that is HARD. It's hard work to make a decision to not try anymore – but based on most of the support available online and from friends/family about "just try again" – it's the thing I'm supposed to do.... [NoLB06, A9]

I never talked on social media or any support groups at the time and generally wanted to get over it just by being with my loved ones, who knew every single bit of the story. [No LB02, A9]

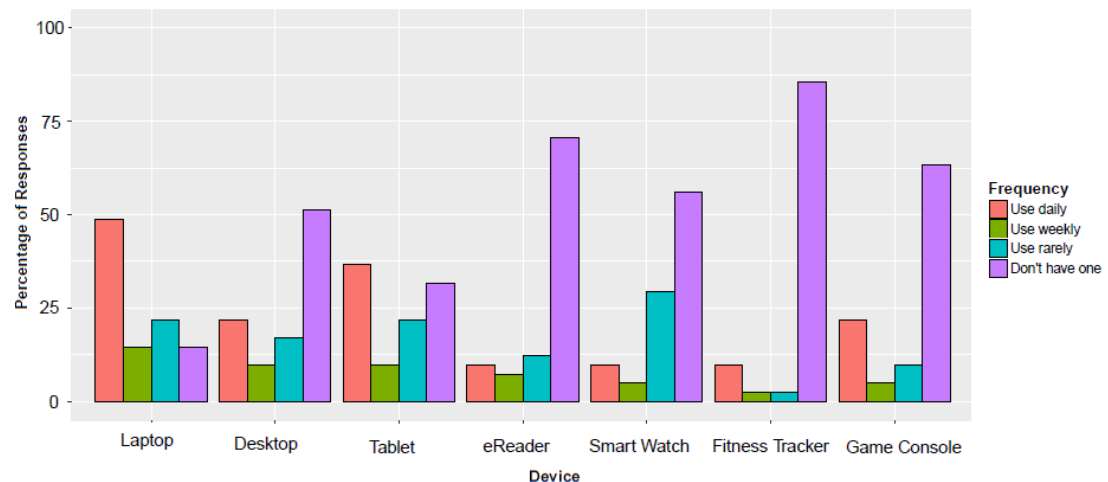


Figure 3.8: Number of participants in demographics survey who indicated that they had a laptop, desktop, tablet, eReader, smart watch, fitness tracker, or games console.

In **A14: Technology Use**, we examined where participants tended to seek tangible support, nurturant support, and informational support online. As summarised in our previous work for the participants in this sample [Alqassim et al., 2019], participants (range (62.5%)–(75%)) utilise online forums mainly as a source of informational support, followed by blogs use (range (31%)–(47%)); and Facebook use (range (22%)–(34%)). When it comes to tangible support, however, forums (59%) and Facebook (56%) are used equally often, with blogs at (22%). Facebook is a key source of online nurturant support for (62.5%), followed by forums (47%) and blogs (16%) [Alqassim et al., 2019].

Participants' device use and social networking footprints, as reported in the demographic survey, were almost as diverse as their care networks. Most participants also had a laptop, and two-thirds owned a tablet, as shown in Figure 3.8. Other devices were less common and used far less often. With respect to social networking account

use (c.f. Figure 3.9), most participants had a Facebook Messenger account. WhatsApp was the second most common additional account, followed by Skype. Moreover, all participants had a smartphone, and almost all used Facebook daily (c.f. Table 3.1). However, this was the only technology use pattern they had in common.

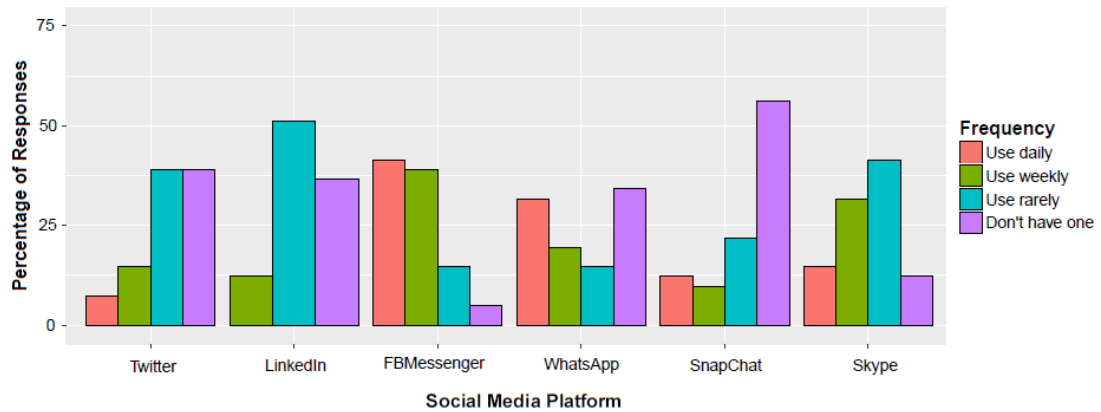


Figure 3.9: Number of participants in demographics survey who indicated that they had an account on Twitter, LinkedIn, Facebook Messenger, WhatsApp, Snapchat, or Skype.

3.3.4.1 Technology Usage Summary

Together with quantitative findings and data on device and social networking account use from the demographic survey, we can summarise that online social support sources sought by participants were varied, although focused on a few online streams, presenting the importance participants place on knowing they are not alone. While online support is an important and promising option, it clearly needs to be tailored to the specific needs of the women who has miscarried, and to the social networks and groups where they feel comfortable. There was no single forum, app or platform that was unequivocally endorsed by all women using it – not even the platform they all had in common, Facebook. We propose that technology can be used to provide services that will enhance the overall delivery of care and social support, as well as to reduce the types of stigma associated with miscarriage, making it easier for those women to find someone to whom they can talk in order to feel that they are not alone. Technology can be used as a means to enable better communication, sharing and exchange of knowledge among the women who have miscarried, and their informal and formal care networks.

Table 3.5: Summary of the social support needs findings

Social Support Type	Summary
Informational Support	<p>Most participants wanted more timely information and suggestions on what to do, guidance on what to expect next, other experience summaries, or at least referral to other resources which would help them to navigate their miscarriage journey. Although most people from the informal care network were placed in either the first or second ring, only partners and miscarriage support groups were seen as trusted sources of informational support, while other members of the informal care network were not regarded as adequate sources of informational support. In contrast, even though less than half of the respondents in A10: Social Support saw the formal care network as including people with whom they would talk about miscarriage, they were identified as the most trusted and preferred sources of informational support.</p>
Emotional Support	<p>Most participants emphasised the need to receive appropriate emotional support from their informal and formal care networks. Regardless of where participants placed their informal or formal care networks in the A7: Circle Diagram, or how much they mentioned them in A10: Social Support, it seems emotional support was required from both care networks. However, partners played a central role in providing emotional support, while family, friends or colleagues who had experienced miscarriage represented people from the participant's informal care network who were very knowledgeable regarding their emotional needs.</p>
Esteem Support	<p>There was substantial evidence that participants did not receive sufficient esteem support during and after their miscarriage experience from both informal and formal care networks. Participants identified that their care network needed to be informed and educated regarding what constitutes helpful comments, and how to provide them to people who have experienced miscarriage. Care networks need to be well-educated on how to react to people who have experienced miscarriage by providing validation and expressing agreement with their feelings and thoughts. The main source of this support was other people who have experienced miscarriage.</p>
Network Support	<p>Participants wanted an easy access to the support group. Other people who have had similar experiences make such a connection as to provide a sense of belonging to participants. Even though relatively few participants mention in-person and online support groups in the A7: Circle Diagram, whenever support groups were mentioned in any of the free text responses, participants talked extensively about the positive role of these groups when discussing their coping strategies and sources of support. However, in-person groups were not always easy to find.</p>
Tangible Support	<p>Participants were satisfied with the tangible support received from their informal network. Most participants who stated a need for tangible support had someone in their informal care network of friends and family who could provide it, although only few of them wanted their informal care network to be a little more proactive in reaching out to them for tangible support.</p>

3.4 Discussion

The data presented here identified the key people in the care networks of women who have experienced miscarriage, the nature of their communications with their care networks, their social support needs, and the technology depended on by women who have miscarried. This study also confirmed the importance of social support in helping women who have miscarried to cope with the physical and emotional effects of their loss.

Our findings highlight the complexity of the formal and informal care networks that are involved in providing social support to women who have miscarried, as summarised in Table 3.5. While the support functions of each part of the formal and informal care networks overlap, our results show clearly that the formal care network dominates with regard to informational support, and the informal care network dominates in terms of tangible support. When it comes to emotional, esteem and network support, however, participants describe receiving better support from similar others [Bellhouse et al., 2018a, Andalibi and Forte, 2018] (i.e. people who had also experienced miscarriage who were more familiar with their experiences and better able to empathise). Despite the differences in participants' individual social support needs, women who have experienced miscarriage have many challenges in common [Bellhouse et al., 2018a]. Participants revealed that providing one type of support was not sufficient to make them feel truly supported, and all types of support were valued. When particular support was needed, which was not being provided by their formal or informal care networks, participants searched for sources of support online. As observed in the literature [Betts et al., 2014, Andalibi and Forte, 2018, Pang et al., 2018], the Internet and social media were often useful sources of such connections.

Though current communication practices existed across the care networks to meet the social support needs of the women who experienced miscarriage, they did so in a complex manner in which multiple online or offline techniques were employed. These communications practices demonstrated the various dimensions of the social support needs of the women who have miscarried, including information, emotional, esteem, network and tangible support. Consequently, these needs extended beyond development of an internet-based psychotherapy programme [Kersting et al., 2011], seeking or posting to internet discussion forums [Betts et al., 2014], self-disclosure and discussing on social media sites [Andalibi and Forte, 2018], or embodying the network-level reciprocal dis-

closure (NLRD) to facilitate exchanging social support at the network level [[Andalibi et al., 2018](#)].

3.4.1 Implication for Service Design

Since participants have many people in their care network who perform different roles, and since participants actively used and coordinated different channels (people, social media, other Internet resources) to obtain the support they needed, we suggest facilitating communication between different members of the care network to share resources to better support the women. There is an opportunity to apply the Circle of Care Model (CCM), which allows care networks to provide a variety of roles (e.g., providing information and helping with chores) and resources that can be drawn on (availability of information about recovery and miscarriage, links to support groups, and so on).

There may be opportunities for designers and information system researchers to support the communication between women who have miscarried and their informal care network (e.g., friends and family), but further study of these challenges from the perspective of this informal care network would be necessary to properly understand the barriers. Instead, we suggest that there are opportunities for women who have miscarried to receive the desired support from each care network, instead of relying heavily on a particular network. [Price \[2016\]](#) argued that better integration of care networks also relieves the load on individual support providers. While all kinds of support are valued, the impact of the support depends on a person's role in the network. However, there are barriers to facilitating social support within the care network. We propose overcoming these barriers by using the CCM to facilitate support among women who have miscarried and their care networks.

Since many of the people in the care network perform different roles to provide support, when creating the CCM, an in-depth communication map covering the formal and informal care networks is crucial. Communication within the care networks of people and providers is crucial, as gaps in communication can lead to unmet needs and, in the worst case, adverse events [[Kripalani et al., 2007](#)]. Since similar others (i.e., people who have also experienced miscarriage, or peers) emerged as a knowledgeable source for most of the social support types – in both informal and formal networks, usually filling the support gap left by the care networks – we identified a category for another level of care and named it the "Peers" category, which might provide the necessary support for the women who have miscarried and their care networks, as illustrated in

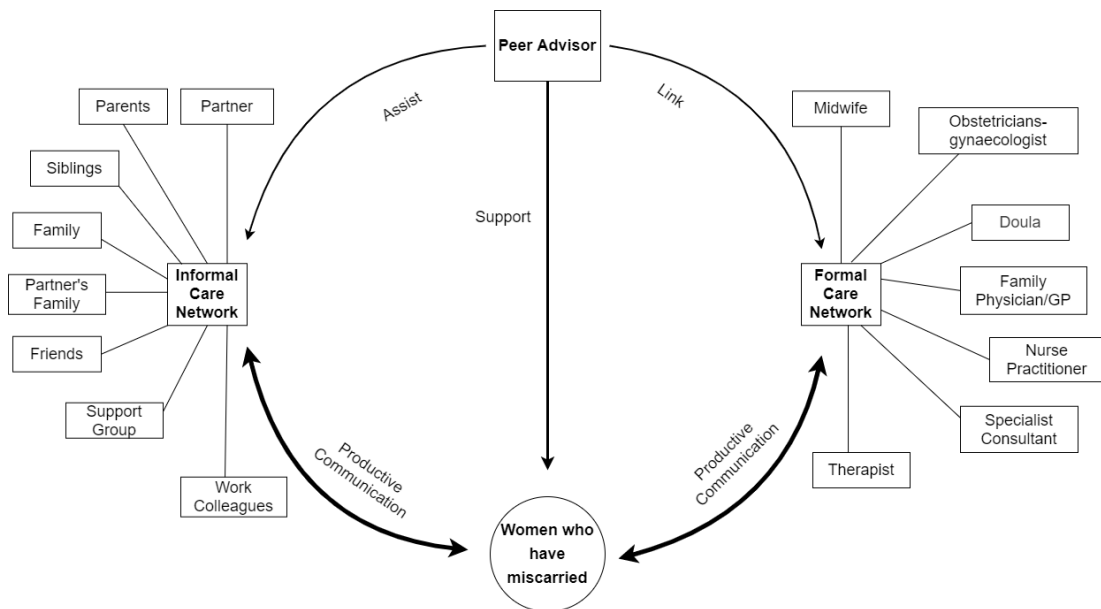


Figure 3.10: Miscarriage Circle of Care Model. Peer Advisor integrated into care networks to enabling better social support communication among the miscarriage circle of care

Figure 3.10. The miscarriage circle of care works through the networks; to keep care flowing in this circle, we must remove the obstacles from its way, and this requires "Peer Advisor" support, with their assistance helping to navigate the obstacles to the flow of care. "Peer Advisor" support might strengthen the miscarriage circle of care, and could help the care networks to become more aware of the support needs of women who have experienced miscarriage, and the needs of those around them, by, for example, sharing stories, experiences and much more besides. However, the miscarriage circle of care needs to be embodied through actions and technology.

Therefore, we suggest mapping the Miscarriage Circle of Care Model (MCCM) of the formal and informal care networks, and their respective roles in providing social support, highlighting the importance of integrating peer support in order to provide holistic support for the woman experiencing miscarriage. The MCCM offers a logical structure of connected concepts that help display of how the social support and the source of support (i.e., care networks) might be connected and relate to one another. MCCM gives us an opportunity to specify and define the communication concept within the social support needs of women who have miscarried. In this research, since we were looking into the social support need of women who have miscarried, relying upon their usage of technology to communicate their needs, our use of MCCM underpinning of

our finding across the research, and allowed us to use the MCCM as lens which helps this conceptualising social support to embedded into technology. Hence, the use of the circle of care by women who have miscarried might be mediated by technology. Technology plays a significant part in being able to apply the MCCM to provide easily access to social support for women who are experiencing or have experienced miscarriage. The communication framework in the circle of care we proposed can draw from formal, informal care networks, and "Peer Advisor" to add further depth and breadth to our understanding of social support communication for women who have experienced the miscarriage circle of care. This notion of the CCM has shown success in end-of-life patient communities (e.g., [Price, 2010]), but has not yet been explored as a way of facilitating social support between women who have miscarried and their care networks. We see this approach as having potential benefits for miscarriage communities, for whom social support is limited and difficult to coordinate.

This study provided insight into the social support needs of women who have miscarried, including their perspective on communication with their formal and informal care networks with respect to these needs. Our research confirmed that women with the experience of miscarriage faced gaps in communication, barriers to receiving appropriate social support from their care networks, and underlying challenges, and also recognised potential opportunities for the improvement of their care networks communications. We proposed the development of the CCM, introducing the idea of "Peer Advisor" to help the circle of care to operate well and deliver the social support that women need during and after miscarriage. We proposed not only linking women who have miscarried to the circle of care to facilitate social support, but in particular enabling people to carry out the roles they have in the circle of care. Such enabling and enhancing could be supported by technology to help overcome barriers to providing social support.

3.5 Limitations and Future Work

The study described in this chapter has potential limitations. The limitations mainly centred about the sample of the participants. The participants in this study were predominantly white, well educated, and established Facebook users which might reflected their use of Facebook as a resource to provide support. Despite our efforts, it was difficult to reach people from lower socioeconomic strata, and people from non-

white populations. As Figure 3.9 suggests, online social media use is highly fragmented, which means that there is no single social media channel that would allow us to reach everyone who is online. Therefore, a different platform, such as WhatsApp, might have given us access to a different population. While most participants were comfortable with disclosing and discussing painful experiences on Facebook, and actively used the platform to seek out emotional and practical support, others were not, and this may have been exacerbated by participants' diverse reproductive histories. In our study, we split participants into two groups depending on whether they had experienced a live birth after their last miscarriage or not in an effort to ensure somewhat similar reproductive health histories, however, this may have been too little differentiation. The **No Live Birth** group, which had lower participation rates, included both women who already had children and women who had decided not to try to conceive again after their last loss. Some participants had a history of recurrent miscarriages, while others had undergone fertility treatment. This study also focused on the women experiencing miscarriage, not on the experience of the people in their formal and informal care networks (e.g. partner), who often also need support [Engel and Rempel, 2015, Farren et al., 2018].

Whilst these are potential limitations, we also argue that this study findings are similar to what may have been expected from looking across relevant literature on the lack of social support provided for women who have experienced miscarriage. This understanding of what the social support type that women who have miscarried struggle to receive allow for better understanding of how the technology could be designed to support the miscarriage experience. Thus, we believe that, despite the limitations, there is value in the findings; particularly the findings where we introduce the MCCM as a promising approach for translating these findings into technology-based services that can improve the lives of the women who have a miscarriage. By describing the many components of the miscarriage circle of care, we have laid the groundwork for designing efficient communication strategies that allow seamless access to social support during and after miscarriage as and when needed.

There are several suggestions in which future work could further validate the study carried out in this chapter. Researchers should monitor the social media landscape to detect emerging alternatives, such as WhatsApp and Skype, and review their privacy policies and practices. Future ARC studies might want to consider smaller, more fine grained groups. Future ARC studies should be mindful of potential effects of study

involvement for participants. Along with this, extra care should be placed into activity design to avoid unintentional emotional burdens for participants, like piloting activities in the targeted populations.

3.6 Summary

Our work toward understanding the social support needs and technology usage of women who have experienced miscarriage draws from several different areas of prior work as discussed in Chapter 2, Section 2.3.2 and Section 2.4.2. In this chapter, we responded to the first research question of this thesis as listed in Chapter 1, Section 1.1. We first identified the people in the care networks of women who have miscarried, with interest in both their formal care network (e.g., health care providers) and informal care network (e.g., family). Second, we examined to what extent the social support needs of women who have miscarried are met and areas where social support is lacking. Third, we discussed the presence of their social support needs in online resource, such as Facebook [Alqassim et al., 2019]. Then, we discussed applying a CCM for mapping the care networks and their respective roles, with the importance of integrating "Peer Advisor" support to provide holistic support for women who have miscarried. Finally, the MCCM was introduced to describe ways of integrating care networks, including better communication and engagement with women who have miscarried and their care networks.

Additionally, in this study women who have miscarried showed their preference for using smartphones. Mobile applications have previously been identified as useful tools for improving the communication between people and their care network [Liu et al., 2011, Tang et al., 2012]. Thus, we realised the importance of designing a social support communication platform that would scaffold the MCCM. Further design investigation was needed to co-design and discover how we might support the experience of miscarriage. In next chapter, we will discuss a possible smartphone application as a technology solution intended to linking women who have miscarried to their circle of care, and enabling their care networks to carry out their roles in the MCCM, and to what extent does the MCCM would be feasible to design for miscarriage circle of care.

*“ No more superheroes, we need
systems and networks “*

Salah S. Al-Rashed

4

Designing for Miscarriage Circle of Care

4.1 Introduction

In this chapter, we will introduce the phase for co-design and feasibility exploration of the Miscarriage Circle of Care Model (MCCM) and technology to enhance social support. The phase consists of five series of workshops that examined the communication techniques of the intervention and enhanced the design requirements.

In this chapter, MCCM serves as the structure and support for the rational for the study, and the purpose of the second research questions. MCCM provide a grounding base for the method and the analysis presented in this chapter. It serves as the guide on which to build and support on this study, and also provide the structure to define how we will approach the study described in this chapter. MCCM undergird our thinking with regards to how we will understand on how the social support need of women who have miscarried will be explored, and specify the direction of this research. MCCM was used to explore scaffolding mechanisms to design such technology and examine with women who experienced miscarriage what kinds of services should be included

and how it should be delivered. We conclude by providing two design scenarios explaining the feasibility of MCCM to enable care networks to carry out their roles and provide holistic social support for women who are experiencing or have experienced miscarriage.

We used the MCCM to develop a the workshop question guide, and tailored the questions to the perceptions of social support, how participants communicated with their care networks within miscarriage circle of care meet their needs, and their technology usage to carry out this study. Furthermore, we drew on MCCM, which served as a socio-technical analytical lens to help gather data on the benefits as well as the challenges of various types of technology applications in relation to miscarriage health services and care. This approach gave us a systematic tool to collect data around various aspects of this research aim. It is therefore used to allow us gaining a meaningful understanding of the complex socio-technical processes that might be involved in the use of technology and services within miscarriage experience.

Specifically, this chapter together with Chapters 5 and 6 are answering the second research question listed in Chapter 1, Section 1.1. The second research question is:

[RQ2] How might we support the experience of women with miscarriage through design?

- How do women who have miscarried communicate with their care network?
- How can we leverage technology to increase social support and make existing social support easier to access?
- How should technology be designed to align to the Circle of Care Model ?

4.2 Methods

After creating common and safe spaces for exploration in ARC study described previously in Chapter 3, we chose to scaffold the design discussions in the one-to-one codesign workshop sessions (i.e., women who have miscarried individually) to focus on exploring and reflecting the individual experiences with the social support needs and care network communication, instead of generic investigation.

While the workshops were structured around **Journey Mapping** activity, we began with an **Icebreaker**, and followed up with a **Post-survey**. **Journey Mapping** is a ser-

vice design method that visualises the experience of the individual over a time as well as potential future experiences, including searching for particular service or recognising a need [Stickdorn et al., 2018]. Researchers utilised journey maps to depict the healthcare service from the patient's perspective to identify problems and suggest improvements [Treble et al., 2010, Treble and Hydes, 2011]. Journey maps help to visually externalise insights and knowledge around patient experience, and promote empathy towards patient groups by placing them at the heart of the modelling process [McCarthy et al., 2016].

In this research, in order to visualise the womens' experience over a miscarriage timeline, we used the **Journey Mapping** activity to help us spot the gaps of participants' communication pattern with their care network throughout their miscarriage journey. Further, utilising the journey map during the co-design workshops would help narrow this down into leveraging technology and spot an opportunity to be informed on how the socio-technical system should be designed to allow women who have miscarried to access their social support need.

4.2.1 Recruitment

Below is the inclusion criteria for recruitment:

1. women who have experienced at least one miscarriage, and
2. who are comfortable taking part in a study that is conducted in English and/or Arabic.

We recruited women through:

1. posting into two Facebook groups that have been created and conducted for the purpose of the previous study [Alqassim et al., 2019], and
2. posting into a Facebook group for our charity and support group partner (i.e., the Miscarriage Association), and
3. the thesis author and supervisor disseminating information about the study through their personal and social media network, and
4. distributing leaflets in libraries and charity shops in central Edinburgh city.

4.2.2 Participants

Five women who have experienced at least one miscarriage indicated their interest to take part in this study. Four participants have experienced miscarriage care in the UK healthcare system, while only one experienced miscarriage care in the US healthcare system. Four participants had a smartphone, with three of them reporting the smartphone as their most favourite piece of technology. All participants actively used and communicated with their social network through various online platform, including social networking sites (e.g., WhatsApp) and social media (e.g., Twitter).

4.2.3 Study Design

During the **Journey Mapping** activity, we presented the miscarriage timeline over the miscarriage journey. This timeline have been identified as part of the ARC study questions which ProHealth lab, Indiana University team were answered, as mentioned in Chapter 3, Section 3.1. Briefly, a miscarriage timeline breaks down into five stages: *Pregnancy Acknowledgment, Early Pregnancy Journey, Trigger Event, Medical Decision, and Recovery*.

To facilitate the **Journey Mapping** activity process, cards were used to guide the participants and allow them to visualise their miscarriage journey. Cards were inspired from the ARC study reported in Chapter 3, and designed using PowerPoint software to help us get a better understanding of their miscarriage journey. The cards came in five categories (c.f. Figure 4.1):

1. People from the formal and informal care networks who can give support and care (e.g., siblings, midwives),
2. Types of social support received or requested (e.g., help with grieving process),
3. Strategies they used that can support them (e.g., meditation or relaxation),
4. Ways in which they communicated or desired to communicate with care network to receive social support (e.g., timely manner), and
5. Technology and devices they used to receive or request the support that they wanted (e.g., blog, eReader).



Figure 4.1: Inspirational design cards used during the workshop (c.f. Appendix I for the list of cards)

4.2.4 The Pilot Study

This design phase started by conducting the pilot study as a preliminary stage for the co-design workshop, with a participant who has experienced miscarriage, to test the co-design protocol. The aim of this pilot was to focus on the flow of the workshop, and to train the thesis author in working on sensitive topics. Note-takers helped the thesis author concentrate on workshop piloting and evaluation, and helped in reflecting on the whole process. From the pilot workshop, we built a second version of the protocols to become much more sensitive in dealing with the participants and the emotions. For example, ice-breaker questions needed to be much less personal and more neutral. Moreover, since every miscarriage is different, the thesis author should first ask the participants to check with them whether the presented miscarriage timeline reflects their experience, or they would prefer to change the stages or rearrange them. Additionally, some cards needed to be duplicate as they might need to be used in more than one place through the journey mapping. Also, there should be mum, sister, and sonographer cards. In addition, the wrap-up session needed to be used for debriefing

the participants.

4.2.5 The Pilot Analysis

We carried out a pilot analysis of three Muslim women who had experienced at least one miscarriage, and who had participated in our co-design workshops. In Section 4.3.6, we report findings of two interesting themes emerging from the experience of Muslim women with miscarriage [Alqassim et al., 2020].

4.2.6 Procedure

Once the participants indicated an initial interest in the study, they received a participant information sheet via email. Participants reviewed the sheet for as long as they liked before consenting and starting the study. Once they were happy to proceed, we agreed on the date and time to run the co-design workshop. Upon the agreed date of the workshop, we anticipated that the participants had read the participant information sheet before the workshop. If not, we asked them whether they preferred us to talk her through it or whether they would like to read it herself before we began. Once the participants agreed to participate and signed the consent form, we carried out the one-to-one co-design workshop. Both sets of participant information sheet and consent form can be seen in the Appendix B.

The workshops began with an **icebreaker** activity to allow some time for the participants to settle in the environment by introducing themselves before asking questions about their miscarriage experience. We posted a colourful post-it note on the wall, where each note has a topic to talk about. We asked participants to pick up one colour and then discuss based on the topic that they found on the note. We used an open prompt of topics, including hobbies, favourite sport or food, things the participants enjoys or what brings them joy and peace (c.f. Appendix J).

Following this, we conducted a **Journey Mapping** activity. First of all, we asked participants to have a look at the miscarriage timeline and checked with them whether the timeline reflects their experience, or whether they would like to change or rearrange it. Then, we asked them to distribute cards where the participants discussed their perceptions of social support, how they communicated with their care networks to meet their needs, and their technology usage. This discussion allowed us to understand the journey mapped and help us brainstorm the type of technology design, with the aim

of trying to expand on technology usage and needs. We discussed with participants the strengths and weaknesses of the existing technology for providing social support, and which techniques they thought were missing during their miscarriage journey. We initiated discussion of a possible smartphone application intended to allow access to their social support needs and communication with the care networks. We provided the participants with a few questions to aid in this mapping (c.f. Appendix J). The participants filled in their miscarriage journey, as shown in Figure 4.2.

Finally, during the wrap-up session (c.f. Appendix J), participants were asked to complete a **post-survey** to help us improve the quality of the next workshop and let us know if they would like to be involved in providing their input and feedback for the workshops findings. Participants received a One4all Gift Card equivalent to £20 GBP for their participation in this co-design workshop.



Figure 4.2: Examples of generated miscarriage journey mapping participants provide.

The workshops took place in a quiet meeting room at the Informatics Forum, University of Edinburgh. Participation in the study lasted approximately two hours. The workshop was digitally audio recorded, with photos and videos recorded only of the generated miscarriage journey mapping that participants produced on the table after the workshop, as shown in Figure 4.2.

4.2.7 Data Analysis

We analysed the qualitative data for the resulting workshop transcripts using content analysis. Content analysis is a structured method for coding, which focuses on describing who said what to whom, and with what effect [Pope and Mays, 2006, Grbich, 2012, Bloor and Wood, 2006]. This involves the identification, examination and interpretation of themes in textual data and asks how these themes helped answer the research questions. Content analysis was chosen as an analytical tool, because the qualitative phase of this research sought to develop a deeper understanding of the issues involved by the communication that occurs between women who have miscarried and their formal and informal care networks, as well as their social support needs and examining the underlying challenges of women using technology. All data collection, transcriptions and analysis were conducted by the thesis author. During the analysis process, the analysis procedures involved gaining familiarity with the data; generating initial codes; searching for themes; reviewing and naming themes; and conducting the analysis [Saldaña, 2015]. For illustration, first, each of the co-design workshops were transcribed manually together with the detailed notes that were taken during and shortly after the workshop sessions and anonymised. Although the transcription process appeared frustrating and time-consuming [Riessman, 1993], it facilitated our familiarity with the data and the content of the workshop, and helped in making an overall sense of the data. Then, the transcripts were examined line by line to allow bottom-up codes (inductive) with top-down codes (deductive) derived from the research questions. The initial codes were compared and combined when overlapping discussion was identified between participants' data, and notes taken from the different co-design workshop sessions. We revisited the codes iteratively until we began to see broader patterns in the data. The codes that have common elements were clustered together into recurrent and high-level themes; these themes were then described by quoted data. Theme has been defined as “a recurring regularity emerging from analysis of qualitative data” [Polit, 2010]. Meetings were held iteratively with the supervisor to debrief and discuss then refine the codes and themes. The multidisciplinary perspectives offered by the supervisor were used to interpret various aspects of the research topic and support a rich understanding of the problem space. Finally, themes were then incorporated according to high-level categories. NVivo software version 11¹ was used to coordinate the coding.

¹<https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>

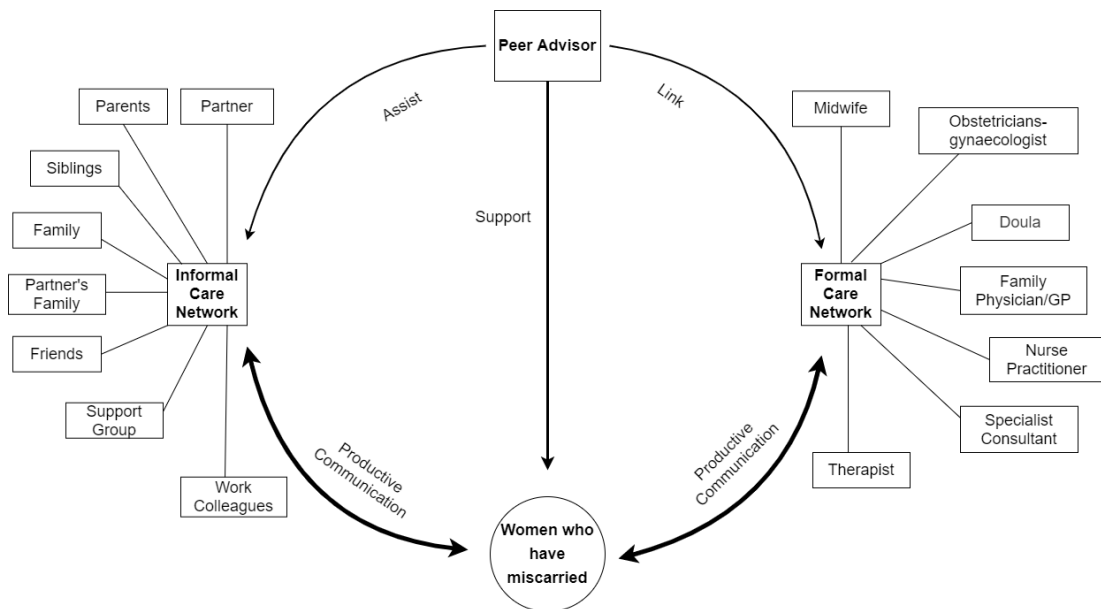


Figure 4.3: Miscarriage Circle of Care Model. Peer Advisors integrated into care networks to enabling better social support communication among the miscarriage circle of care

4.3 Findings

Throughout the journey mapping activity, participants described situations where they communicated their social support needs to their informal and formal care networks through various means to help them navigate their miscarriage journey. Participants demonstrated situations where they used technology and online services that have been helpful, or in the future might be helpful to access the support they want. There are five primary themes that emerged from the data as presented in Table 4.1.

4.3.1 Being Prepared

Participants discussed their underestimate on the commonality of miscarriage and that they were unprepared when a miscarriage occurred. Participants discussed wanting general recognition of the risk of miscarriage by providing general information about miscarriage from their formal care network during early pregnancy. Participants stated that there was a need for clear, upfront general miscarriage information regarding the eventualities in early pregnancy. Thus, women would be more prepared and aware of what to expect and what to do next in the case of a miscarriage.

Table 4.1: Summary of codes used in analysis. Number of participants refers to participants who made at least one comment during the workshops that was classified as that code. Total instances is the number of comments classified as that code.

Codes Name	# of Participants	Total instances
Being Prepared		
Miscarriage recognition on early pregnancy	4	6
Underestimate how common miscarriage is	4	4
Dealing with Uncertainty		
Seeking trusted information	5	8
Waiting for confirmation	4	4
Experiencing symptoms and anxious	3	5
Peers' Experience		
Reading other's stories and experience	4	8
Difficulty accessing network support services	2	6
Dealing with Feelings		
Help managing the grief	5	8
Inadequate emotional support	3	7
Raise Awareness		
Training the formal care network	4	8
Educate informal care network	5	10

In this early stage, the professionals could have done a better job of saying, hey, this happens, they could provide me with some information. It could have said, by the way, if this happens to you, at least I would have known where to go. [P2]²

4.3.2 Dealing with Uncertainty

Participants felt distressed while they were concerned about the viability of the pregnancy. Participants were frustrated by the limited, trusted, and reliable information about the clear next step when they were uncertain about their pregnancy, and waiting for appointment or scan results to confirm their miscarriage.

²Participants are labeled based on their participant number (P#)

There should have been more information or if [the professionals] do not have time to give you information they could have at least referred you to. Here is a good website here is a good information here is our doctors' site.
[P3]

Participants described this as a particularly difficult time because they were anxious about the viability of their pregnancy and at the same time putting in effort to find out what was happening. Therefore, they extensively described their attempts to gather precise information online to help them understand what is normal and what is not normal that could happen during pregnancy.

There should be a particular tool focusing on providing information about the symptoms and diagnosis of miscarriage. That would prevent me from spending a lot of time between a bunch of information. [P4]

4.3.3 Peers' Experience

Participants outlined reading other womens' stories through online resources to come to terms with their own experience as an attempt to support themselves through finding other people who experience similar situations (e.g., symptoms), or other people's stories on how they cope and recover physically and emotionally. However, participants desired reading those experiences through accredited or professional services.

I turn to trusted website health information and online forums once the symptoms started to read about other women experience and whether their pregnancy completed after the symptoms or it ended up with miscarriage.
[P1]

A P5 shared her experience when she utilised website search engines to find an in-person support group as a safe space to reach out to other women who had experienced miscarriage.

I do remember how it was hard to find out information about in-person support group in website, and a lot of these website are old. So, I do not know the exact day and time because I am not in the situation to search and find out.

4.3.4 Dealing with Feelings

Participants acknowledged that they felt it was hard to understand their feelings following miscarriage, and found it even harder to articulate those feelings.

It takes too much time to understand my feeling. We have the discrimination between the types of feelings. I wish to diagnosing my feeling by a

trustful specialist who could explain my feeling. I do not like to share my feelings with any people or family. I do not want to hurt them by sharing those feelings. [P4]

They described a clear need for information from those who are skilled (e.g., therapist) during the recovery stage to help them understand their feelings and circumstances to better navigate their emotional journey.

There was some information, help with self-care from the medical side. They tell so much on what to expect from physical side, but I have not got as much information as I would like about emotional effect side. They gave a portion of information but not enough about emotional side. [P1]

4.3.5 Raise Awareness

Throughout the study, all participants revealed that there is a need to create more awareness and support for people following miscarriage and that people in their formal care network need to be trained on how to respond appropriately to their miscarriage by using sensitive language when delivering bad news and acknowledging the loss, as P5 shared.

I would teach every one in the society to use the right language, use the language of grief, not the language of medicine, and to think of that way we lost a member of family. [P5]

Sometimes informal care networks do want to be helpful, but sometimes they do not know how to respond to the miscarriage; their attempts at being helpful sometimes have a negative impact. Participants stated that people in informal care networks sometimes were not educated enough on how to react to miscarriage. This sparked participants to shift from focusing on their own grief and recovery to educating others about how painful miscarriage is and it is a real loss despite it happening in early pregnancy.

Thank God that I am good for now, but I want to tell everyone that what happened for me was not easy either physically or mentally. It is like actual delivery but without having the baby. [P1]

4.3.6 Spiritual Dimensions

As mentioned previously in section 4.2.5, three Muslim women who have experienced at least one miscarriage engaged in this co-design workshops. In this section, we report two main themes that emerged from our pilot analysis as an attempt to answer a question of how do Muslim women cope with miscarriage?

Theme one: Trusting Allah

During miscarriage, participants' faith in Allah and trusting Him was the most important strategy that brought them comfort. The sense of surrender to God's will, and accepting what happened, brought them the strength that they needed to cope with their loss.

I have a strong belief in Allah [God] and I am satisfied with what happened to me. [P1]

Theme Two: Pray and Supplicate

Participants' relationship with Allah and Islam was redefined after miscarriage. Participants extensively described the level of comfort that prayer and supplication provided them. They listened to the Qur'an throughout the day, and that was the ultimate source of support to recover emotionally.

Keep saying zikr (Subhan Allah) and listening to Qur'an thorough the day helping me a lot to cope emotionally. [P3]

These findings suggest access to spiritual resources is important given that religion is crucial to participants' recovery. Resources might include a discussion of what miscarriage in Islam means, stories about Prophet Muhammad's (peace be upon him) companions who had experienced miscarriage, and information about the reward from Allah to women who have lost their pregnancy. Technology might play the main role in providing access to spiritual resources. This spiritual dimension, which is so important not only for Muslim women but for any women in the faith community of which there are many in the West, is often neglected in Western literature on miscarriage. The concept of spirituality in Muslim, or any faith community, womens' models of caring needs to be explored in the light of miscarriage and the broader discourse on the spiritual life that could be an aspect of the circle of care. Further investigation is needed to help researchers design a solution that addresses those needs, and iteratively test them with Muslim women before consulting a range of stakeholders [Alqassim et al., 2020].

4.3.7 Digital Technology and Privacy Concerns

Although the sample who participated in this study were actively using various online platforms and mobile applications (as presented in Section 4.2.2), when it came to their miscarriage journey the focus was on the technology channels used. Throughout the participants miscarriage journey, four of them used their smartphone to communicat-

Table 4.2: Participants' use of technology and social platforms for seeking social support during the miscarriage journey

	P1	P2	P3	P4	P5
Smartphone	✓	✓	✓	✓	-
Laptop	✓	✓	-	-	✓
Desktop	✓	-	✓	-	-
Phone Calls	✓	✓	✓	✓	✓
Text Messaging	✓	✓	✓	✓	✓
Website Information	✓	✓	✓	✓	✓
Online Forums	✓	-	✓	✓	✓
Guidance and Advice	-	✓	-	✓	✓
Helpline Call	✓	-	✓	-	-
Blogs	✓	-	-	-	✓
FAQ	-	✓	-	-	✓
YouTube	✓	-	-	-	-
Capturing Photo	-	-	-	✓	-
Facebook	-	-	-	-	-
Online Support Group	-	-	-	-	-
Podcast	-	-	-	-	-
Instagram	-	-	-	-	-
Twitter	-	-	-	-	-

ing their information and support to their care network. Text messaging was among the few mobile applications, and participants communicated with their informal care networks using occasional one-to-one text messaging and phone calling using their smartphones. In contrast, the communication channels used to connect with their formal care network was limited to phone calls or formal helpline phone calls (e.g., NHS 24) using their smartphones. Smartphone has been emerged as a common device to use by participants in communicating their social support needs to their care network due to its mobility and availability, and only P5 reported that she does not use a smartphone. Additionally, participants confirmed the importance of having an open communication line either asynchronous (e.g., email/mail) or synchronous (e.g., phone call) with a formal care network for ongoing support, especially at sensitive stages where timely

responses are important.

When particular support was needed, which was not being provided by their formal or informal care networks, participants searched for sources of support online. As observed in the literature [Betts et al., 2014, Pang et al., 2018], the technology and online boards were often useful sources of such connections. While participants searched for information on the web and online forums, almost all of them worried about the reliability of the information. Therefore, participants searched for information on trusted and recommended websites that were certified by doctors or credential organisations as an attempt to gather reliable information mainly about their symptoms, other women's experiences of miscarriage, and the latest research about miscarriage. This initial information search was followed by online forums. While only three participants used the guidance and advice websites (e.g., National Institute for Health and Care Excellence) as trusted resources, the other two reported that they were not aware of these websites to gather accurate guidelines.

Contrary to previous findings [Alqassim et al., 2019], participants did not use Facebook as a source for social support for their miscarriage experience, even those who were regular Facebook users, nor other social media platforms such as Instagram and Twitter. Several reasons were mentioned for preferring not to use social media, including concerns about privacy on social media applications. Those findings suggested that participants focused on a few online information streams and support.

4.4 Discussion

This design phase focused further on exploring the existing communication behaviour of the women who miscarried, and discussing the feasibility of MCCM to provide appropriate social support as one possible support mechanism and approach. The miscarriage journey mapping was developed to guide us through visualising the MCCM and the communication patterns between women who have miscarried and their care networks (c.f. Figure 3.10). These five miscarriage journeys maps responded to the second research question second listed in Chapter 1, Section 1.1, thus served to:

1. described the common communication that occurred (or did not occur) between care networks and women who have miscarried;

2. captured challenges of the situation that women faced related to receiving social support;
3. understand the kind of services and technologies that should be designed to provide social support and respond to the identified challenges within the MCCM.

Participants' miscarriage journey emphasises their care networks' roles in the MCCM, as care networks roles were discovered that had significant impact on improving women's wellbeing and providing their social support needs. We conclude this section by providing two example scenarios of how the MCCM would operate.

4.4.1 The Feasibility of the Miscarriage Circle of Care Model

The findings of these co-design workshops reiterate a substantial lack of informational and nurturant (emotional, esteem and network) support for women who have experienced miscarriage, and an appropriate social support was seen as important for navigating this emotional journey. A core problem that participants faced was the insufficient knowledge of what miscarriage is before experiencing one themselves. This makes them devastated with complex needs and difficult communication with their care network while in a raw emotional state, and often with limited informational and nurturant support at the time.

Therefore, there is a clear need for an improvement in social support provision to be provided earlier on to assist women to understand the potential risks of miscarriage and provide an idea of what to expect if they miscarried. Information could include facts about the commonality of miscarriage, and how to cope physically and emotionally if this happened. Overall, participants desired to be prepared by having more access to miscarriage general information throughout their journey and to be provided from a trusted, reliable formal care network. This means that participants might benefit from being guided and supported by those who could provide accurate support through the miscarriage journey, from Early Pregnancy Journey to Recovery stages. **The MCCM could be integrated into a pregnancy care model where social support and care network communication could be monitored and a seamless transition could be provided to miscarriage resources and support once needed.**

Given that stigma associated with miscarriage [Andalibi and Forte, 2018], network support was needed to be accessible to reach out to other women who have experienced miscarriage who are not well recognised in society. Reading other people's ex-

periences, and relevant network support services, needs to be authoritatively available and easily accessible. **MCCM might help connecting women who have experience miscarriage into "Peer Advisor" care level through a one-way connection, where women can read others' experiences and stories without revealing their own.** Further, **MCCM might have a role in connecting women with such emotional support services privately through "Peer Advisor" or formal care networks, with providing a lot more specific information and support that helps women understand a range of complex emotions following miscarriage.** Those services would help women understand their feelings or openly talk about their experience and thoughts without judgment.

Moreover, formal care network need to become more trained and informal care networks need to become more educated, on how to provide effective support. Therefore, we also need to raise the overall community's awareness on how miscarriage affects women emotionally and physically. **The MCCM might fill this need by connecting those who have knowledge (e.g., Peer Advisor) to give such guidance with people in the care network to help them understand miscarriage circumstances.** Therefore, care networks would be trained or educated without putting for the onus on the women experiencing miscarriage to do this while their grief is in a raw emotional state.

Smartphone emerged as common device used by participants to communicating their social support needs to their care network. Additionally, although participants benefited from health websites and online forums, these online technologies bring with them issues of trust and reliable information, and they reluctant to take random information into consideration. Moreover, they sought accredited technology provision to increase the information's reliability, and the reliability of provided social support throughout the entire miscarriage process. **The MCCM might help in connecting women during their Trigger Event stage, when they become concerned about their pregnancy, to an authoritative source (e.g., formal care network) in a timely manner.** This connection and information can be easily presented during the early pregnancy, so that it is readily available, and can be consulted as needed across the rest of the journey.

4.4.2 Design Scenarios

Here we provide two example scenarios of how MCCM enable the care network to carry out their roles, and how social support might be exchanged within the miscar-

riage circle of care. While we were designing the scenario, we considered the two main categories of social support that are derived from the two main networks (i.e., formal and informal care network) identified in the MCCM. Scenario 1 preset our envision for women who have miscarried who communicating the formal care network to seek **Action-facilitating** support. Scenario 2 preset our envision for women who have miscarried who communicating the informal care network to seek **Nurturant** support.

Scenario 1: Communicating Formal Care Network

One conversation that took place in this study was around how it was difficult to find an in-person support group. This was something that participants mentioned searching for to help them cope following miscarriage.

We imagine women who have just miscarried might want to escape from what has happened. She does not want to engage with people but does want to talk to people who understand what she has been through. She is not sure how to find out more information to support her and cope with miscarriage. There is a lack of information available about where to go or how to find support. To eliminate the obstacles from finding timely information and facilitate these kind of support needs, it would be ideal if midwives, as a trusted source of informational support, were linked with a group of women who have miscarried and who are volunteering to provide support for women in the community who have miscarried. The midwife then could provide the women with a list of credentialed local support groups that she could attend in-person or online. Since the MCCM could link the network into the miscarriage circle of care, women who have miscarried would have easy access to very specific information about these groups, including the location, day and time of those meetings. Technology can play a significant part in applying the MCCM and enhancing communication between the care networks to better support the women who have struggled with feelings and thoughts.

Scenario 2: Communicating Informal Care Network

Another conversation that took place in this study was around the fact that participants' care networks wanted to be supportive, but most of the time made comments that may have been intended as caring and supportive, but came across as unhelpful.

We imagine that parents, who have no direct miscarriage experience, struggled with what to say and how to react to their daughter's miscarriage (e.g., the phrase to say and how to say it). Because miscarriage is not a commonly or openly discussed topic, peo-

ple are not informed on how to react or provide support. To eliminate the barriers and facilitate this type of support needed, it would be ideal if "Peer Advisor" directly contacted the parents, through the link within the miscarriage circle of care, and provided useful information on how they can offer helpful comments, how they can support their daughter and what type of help she might need during this time. Alternatively, if the "Peer Advisors" member was not available to provide support, the formal care network could provide guidelines on what to say and how to say it. The MCCM perhaps can help make the miscarriage less of an embarrassment, so people can get the facts and understand the feeling of miscarriage. This can relieve women of much of the work of communicating both the facts and the emotional impact of a miscarriage to their circle of care. This would be particularly useful in a case where a member of the informal care network would like to help but does not know how best to provide support [Bellhouse et al., 2018b]. Technology plays an important role in applying this model, for starting to talk and engage in a good level of communication about miscarriage. The more conversation and communication that happens between those women and their care networks, the more people will know how to talk about miscarriage and deal with miscarriage.

4.5 Limitations and Future Work

The work described in this chapter is subject to potential limitations, and the conclusions drawn should be considered in light of these limitations. Validity and reliability are important in showing that any study can be generalised to the population at large [Kelly, 2009]. The limitations of this study centre mainly around the small sample of participants and small number of methods used. Participants of this research were more comfortable talking about their experience and this may tend to make them feel more empowered about their miscarriage experience, and their miscarriage experience may be different from women who are less comfortable women with their experience of miscarriage. Additionally, women participated in the work described in this chapter were actively use their smartphone and social network mobile applications, thus, they are likely to be early adopters for mobile application; they are already willing to be helped through technology. Another aspects of our study that restrict our ability to immerse in data is the study design and methods used as the workshop were mainly focused on the Journey Mapping activity. The study could benefits from using another method during or following the workshop to allow triangulation of the

data. For example, while we send a post survey to participants, some questions could be included in the survey to ask participants about their opinion on a future mobile application as a digital solution to support the experience of miscarriage.

Despite these limitations, we argue that our findings provide actionable input for the design of MCCM for concrete miscarriage care. The study help us establish a better understanding of the current use of technology by women who have experienced miscarriage, and to explore participants' views on, and the possibilities for, mobile application as a solution. The MCCM provided the boundaries of a useful system for this study, with a comprehensive view of what we observed for the ARC study reported in Chapter 3 in terms of the care networks, communications and social support needs related to women who have experienced miscarriage over their miscarriage journey.

Future work might build on this foundation by considering less digitally connected participants. Women who did not have access to online resources or were less engaged in using smartphone such as P5 may also have a different perspective, since they would need to seek support elsewhere and differently; and they not already willing to be helped through mobile application.

4.6 Summary

Our work towards understanding the social support needs of women who have miscarried is drawn from several previous works. In Chapter 2, Section 2.3.2 and Section 2.4.2, we provide a foundation from which to explore the social support needs and the nature of the communication between women who have miscarried and their care networks. In Chapter 3, we found that women who have miscarried face barriers to receiving appropriate social support and encounter substantial barriers when communicating with their care networks. This makes it more challenging to receive appropriate informational, emotional, esteem and network support. We proposed the development of the MCCM, introducing the idea of "Peer Advisor" to help the miscarriage circle of care to operate well and deliver the social support that women need during and after miscarriage. In this chapter, we reiterate a clear need for technology that links women to people in the MCCM, and helps them meet their varied social support needs. Such technology should proactively provide efficient communication that allows seamless access for women to their care networks, and to relevant social support. In Chapter 6, we will use the MCCM to design a prototype of mobile application

solutions that allow seamless access to social support during and after miscarriage as and when needed.

However, we believe that the requested social support might not be accessible and achievable without putting effort into improving usability and accessibility of social support provisions. For example, if the user's mental model accurately matches the technologies, the user can better use the mental model to perform their tasks. If technologies' mental model is inaccurate, however, the user will make poorer choices about what actions to take, may not be as happy, and may be less productive. Therefore, next chapter describe our attempt to understand the mental models of women who have experienced miscarriage to support the prototype design of a mobile application and make it more intuitive to the users.

*“Strength lies in differences,
not in similarities “*

Stephen Covey

5

Understanding Mental Models of Miscarriage to Support App Design

5.1 Introduction

Miscarriage Circle of Care Model (MCCM) is guiding the overall design of enabling women who have miscarried to easily access their social support needs through the miscarriage journey. However, the experience of miscarriage changes the perception of social support, hence, the detailed design needs to take this into consideration. We do this by investigating “mental models” of how women who have experienced miscarriage classify and cluster support. Understanding the mental models of women who have experienced miscarriage will help supports us to design based on those women’ expectations, thus making the resulting design intuitive for them [Bernard, 2000, Carroll and Olson, 1988, Revell and Stanton, 2012]. This is contrasted with women who have not had experience miscarriage, and this informs the detailed design of the prototype of a mobile application and make it more intuitive to the users by providing insight into how women who have experienced miscarriage understand formal and informal

support. Women who have miscarried are likely to have a different mental model of the system based on their miscarriage experience, social support needs, knowledge and attributes.

Since users differ in terms of the knowledge they possess and their experience, understanding how these differences influence target population behaviours will help design systems that are better suited to a target group. Therefore, we thought it would be instructive to including women who have not miscarried in the process as seeing the difference sensitises the designers and give them the correct way of glasses to see things; hence, we understand better, and can design specifically for the group who have experienced miscarriage. Therefore, this chapter review the role of the mental model in understanding how women who have experienced miscarriage perception of support differs from those who have not by the use of the clustering and classifying uncovered by the card sorting exercise provides a form of mental model. The study combined with results derived from the workshops described in Chapter 4 to help understand the key requirements and mental models of women who have experienced miscarriage and thus help responding to the second research questions listed in Chapter 1, Section 1.1.

5.2 Method

5.2.1 Recruitment

The online card sorting was advertised on Prolific Academic, a crowdsourcing platform, as the study "Weaving the Miscarriage Web of Care" with an estimated time of 30 minutes and compensation of £5 GBP. We also recruited participants from the ARC study Facebook groups, who were sent the link on expressing interest and compensated with a £5 GBP Amazon voucher. Prolific Academic is regularly used for advertising academic study [Peer et al., 2017]. We also recruited women through posting into a Facebook group for our charity and support group partner (i.e., the Miscarriage Association), and the thesis author and supervisor disseminating information about the study through their personal and social media network.

Below is the inclusion criteria for recruitment:

1. women who have experienced at least one miscarriage, and
2. women who have not experienced miscarriage themselves, but had a friend, family member or colleague has experienced one or more miscarriages,

3. who are comfortable with taking part in a study that is conducted in English.

We involved women who have not experienced miscarriage in the research to better explore the different clustering and classifying behaviour between women with experience of miscarriage and those without miscarriage experience. This is a key insight into how the experience of miscarriage changes perception of support and this is important to understand for designers who have not experienced miscarriage.

Moreover, since women who have miscarried were formerly women who have not, and once they have miscarried they have transferred from being pregnant or with no miscarriage experience into women with miscarriage experience, and thus leading to the design of, among other things, a mental model employed by women who had no direct experience of miscarriage. Involving women who have not miscarried helped understand the nature of the transition from being women with no miscarriage experience into women with miscarriage experience. Thus, accommodating those detailed design within the prototype may facilitate easier access routes so that women who are experiencing their first miscarriage and transferred from a group to another can take full advantage of the designed technology. This may be the first step in reducing the digital divide.

5.2.2 Participants

The total number of individuals who attempted the card sort was 141. Of those, (N=47) participants abandoned the study, as they did not actually sort any cards or complete the sorting. A total of (N=94) who truly attempted the sort, completed and saved their sort. The following results cover (N=32) participants who reported that they had not experienced miscarriage themselves, but they had a friend or close colleague who experienced one or more miscarriages, and (N=48) participants who reported that they have experienced at least one miscarriage; (c.f. Table 5.1). Researchers suggest that 20-30 participants is reasonable to obtain robust data from open card sorts [Tullis and Wood, 2004], thus our studies had adequate sample size.

5.2.3 Study Design and Procedure

In this study, we utilised online card sorting method as it *“can provide insight into users’ mental models, illuminating the way that they often tacitly group, sort and label tasks and content within their own heads”* [Morville and Rosenfeld, 2006]. The

Table 5.1: Participants use of devices reported in online open card sorting activity. **EM** = participants who have experienced miscarriage, **NoEM** = participants who have not experienced miscarriage. N = number of participants (percentage of N)

	Daily	Weekly	Rarely N (%)	Do not have one	Not reported
Smartphone					
EM	45 (94)	1 (2)	0 (-)	1 (2)	1 (2)
NoEM	30 (94)	0 (-)	1 (3)	0 (-)	1 (3)
Laptop					
EM	28 (59)	7 (15)	6 (12)	4 (8)	3 (6)
NoEM	18 (56)	5 (16)	5 (16)	4 (12)	0 (-)
Desktop					
EM	14 (29)	4 (8)	9 (19)	19 (40)	2 (4)
NoEM	6 (19)	6 (19)	2 (6)	17 (53)	1 (3)
Tablet					
EM	9 (19)	8 (17)	13 (27)	14 (29)	4 (8)
NoEM	8 (25)	8 (25)	5 (16)	10 (31)	1 (3)
eReader					
EM	3 (6)	6 (13)	6 (13)	28 (58)	5 (10)
NoEM	1 (3)	7 (22)	3 (9)	19 (60)	2 (6)
Smart Watch					
EM	2 (4)	3 (6)	0 (-)	37 (77)	6 (13)
NoEM	5 (16)	0 (-)	3 (9)	21 (66)	3 (9)

card sort has been used as a quantitative and qualitative data collection technique in many health [Morse and Field, 1995], social sciences [Ryan and Bernard, 2000], user experience and HCI disciplines [Rohrer, 2014].

Open card sorting allows participants to create their own names for the categories and have the freedom to classify cards according to their experience and knowledge [Nawaz, 2012]. Unlike the other types of cards sorting (i.e., closed and hayride) where participants are provided with a prearranged group of category names. Therefore, we chose to apply open card sort in this study to:

1. assist identifying how women who have miscarried mentally classify the cards

Table 5.2: List of cards used on online cards sorting

Categories	List of Cards
People who can give support	Partner, Parents, Siblings, Midwives, Health Visitor, Therapist, Sonographer, Partner's Family, Friends, Support Groups, Work Colleagues, General practitioner, Gynaecologist/Obstetrician, Nurse Practitioner.
Types of support to receive	I want to feel heard, I want help with traveling and appointments, I want help with chores (Laundry, Cooking, etc), I want it to be easier to ask for and coordinate help, I want help with childcare, I want help with self-care, I want help with the grieving process.
Ways to receive support	In a timely manner, Privately, Easily accessible, Online, In a safe way, Anonymously, Personalised information and support, In a shared forum, Face to Face, In social situations, Is actually supportive,
Time to get the support	When I find out that I am pregnant, When I am pregnant, When the symptoms that end in miscarriage start, When I find out about the miscarriage, When my miscarriage is medically managed, When I recover from the miscarriage.
Techniques to get support	Attend in-person support groups, Email people, Contact an email helpline, Visit online forums, Video call people, Text people, Write letters, Access information while I am with others, Listen to podcasts, Read useful websites, Talk to people on Facebook, Read useful blogs, Reach out by phone, Reach out to a phone helpline, Meditate or relax, Find out about the latest research, Find time to rest, Write in my diary, Connect with an online support group, Connect with a face-to-face support group, Read books and quotes that inspire, comfort, and support me, Track my activity, Connect with a therapist, Play games, Watch videos.

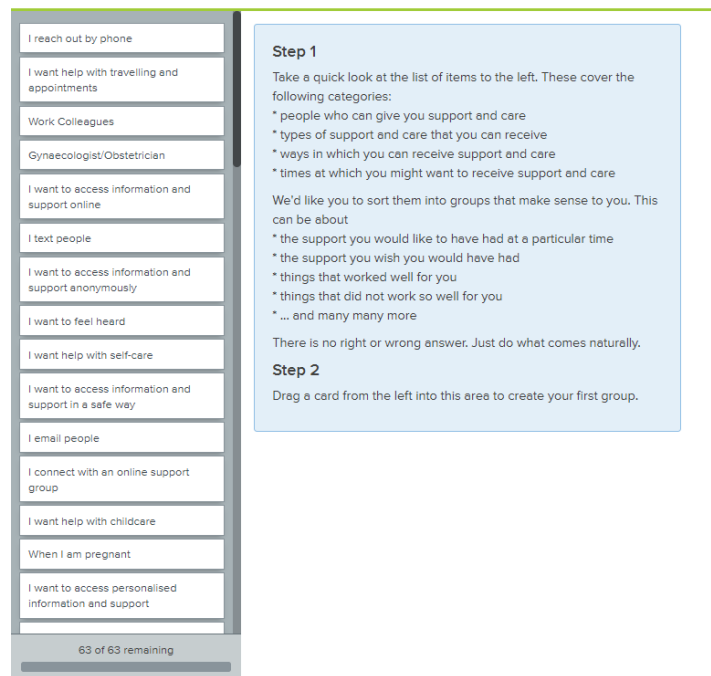


Figure 5.1: Card sorting instructions and interface of OptimalWorkshop (c.f. Full documentation of online card sorting steps can be found in Appendix K)

and what terms participants use for the categories, which provides insight into those women perception of social support.

2. to uncover patterns in how participants clustering the cards, which consecutively helps induce ideas for those women perception of social support, and detailed design.

Card sorting method can be applied in a typical face-to-face session or by using suitable tools designed to moderate the process remotely/online [Paea and Baird, 2018, Righi et al., 2013]. The cons of an online card sorting approach compared to the face-to-face one is that we do not get information on why participants sort the cards the way they do, because we cannot see the participants or hear them thinking out loud [Petrie et al., 2011, Nawaz, 2012]. Thus, face-to-face card sorting would have been helpful for us to gain a clearer idea of participants' reactions and thought processes. Nevertheless, in this study, we carried out an online card sorting method, instead of face-to-face for the following reasons:

1. to satisfy the constraint of collecting a relatively large sample size of data.
2. provides less costly and easier to reach a more, broader geographical diversity of women who have experienced miscarriage and women who have not in a

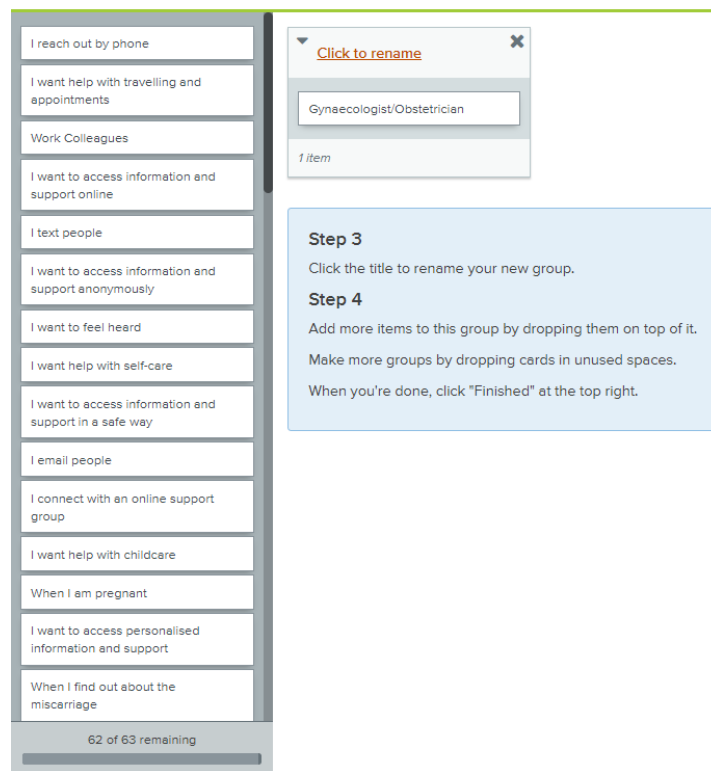


Figure 5.2: Card sorting instructions and interface of OptimalWorkshop (c.f. Full documentation of online card sorting steps can be found in Appendix K)

reasonable amount of time.

3. participants were able to complete the card sorting exercise on their own time.
4. since online card sorting can be conducted using several software programs, this provides us with an electronic data set of categories and the cards placed under them [Paea and Baird, 2018, Righi et al., 2013].

We carried out an online open card sorting study using the web-based service provided by OptimalWorkshop ¹. The online card sorting started with presenting the participants information sheet where participants provided their informed consent online, after reading participants information sheet (c.f., Appendix K to see the sheet). Then, participants completed a short questionnaire that focused on identifying participants' experience with miscarriage. We also asked participants about their devices and frequency of use. There were no demographic related questions (c.f., Appendix K). Following this, participants were given instructions on how to use the online card sorting tool, and how to sort the cards in categories that make sense to them and subsequently

¹<https://www.optimalworkshop.com/>

labeled each category (c.f. Figures 5.1 and 5.2). Then, participants started a typical open card sort. Participants were given 63 cards. Cards were inspired from the findings of the ARC study (c.f. Chapter 3), and designed to contain one word or phrase as shown in Table 5.2. Participants were not required to sort all the cards. The cards were also randomised for each participant. Following the card sorting activity, as part of a debrief, we asked the participants if there were any thoughts they would like to share. This was asked to eliminating the cons of online card sorting by providing opportunities to learn how participants represent themselves.

5.2.4 Piloting Card Sorting

We pilot tested for the designed card sorting with three sample participants: two were women who have not experiencing miscarriage, and one women who had experienced miscarriage. The aim of this pilot was to spot any kinks or issues before the study is launched. We test the clarity of the instructions, wording of the cards, the logistics for which the card sorting will be administered, and to mimic the real card sorting study situation as much as possible. We found that a post-study debrief with the pilot test participants was particularly helpful. They were able to highlight where they struggled, which we then got to address before the launch of the study. For example, we provide detailed instructions for the participants on how to sort the cards and labelling the groups (c.f. Appendix K to see the instructions).

5.2.5 Data Analysis

This section presents our analysis of the data collected from online card sorting activity. Following [Spencer \[2009\]](#), we ran an exploratory Categories' Labels Analysis (CLA) and statistical Hierarchical Cluster Analysis (HCA) algorithms to understand the mental models of how women who have experienced miscarriage classify and cluster support. The resulting **standardised labels** and **dendrograms** from our analysis of the card sorting provide a fine-grained analysis of how women perceive support and this will influence the detailed design of the app.

5.2.5.1 Categories' Labels Analysis

First, we ran exploratory Categories' Labels Analysis (CLA) using standardised label technique. We created a list of all the categories that emerged from participants. Then,

we began our data analysis by first excluding some participant's data (N=14) for analysis during "cleaning" the data process. We removed participants' data that the labels of the categories were meaningless to the research purpose, such as "Group A" and "R-1", since there was no chance to ask or reflect with participants on the meaning of those labels. The ambiguous categories' labels will not be of much use in helping us derive participants' mental models, while meaningful labels might provide valuable information on participants' key requirements [Righi et al., 2013].

We also removed participant's data that took very shorter time from the median (10:12) to complete the card sorting across all participants as suggested by Righi et al. [2013]. While it was important to look at the time participants took to complete the task sort, we removed participants' data by judging the completion time as well as the quality of the label.

Finally, we combined the categories based on the similarity of the words or ideas. We labelled each combined group with **standardised term** according to which words had been used most by participants. The resulting **standardised labels** of categories classified by women who have experienced miscarriage are shown in Table 5.3, while the **standardised labels** of categories classified by women who have not experienced miscarriage are shown in Table 5.4. We used the OptimalWorkshop web based service for classifying the categories' label.

5.2.5.2 Hierarchical Cluster Analysis

We also ran statistical analysis using Hierarchical Cluster Analysis (HCA) algorithms to highlight patterns in the data. HCA is typically used to create a dendrograms, and it is the most common method used to analyse card sorting results [Chaparro and Hinkle, 2008, Katsanos et al., 2019]. R programming for statistical computing software version 4.0.2² was used to make a calculation of the distance between cards using the Euclidean Distance measure to calculate the distance between cards. Then pairs of cards placed in a group by lots of participants have a low distance score (they are close to each other), and cards placed infrequently in a group have a high distance score (they are farther apart). With the initial distance calculation, the R software combines the closest two cards into a cluster and recalculates the distance measure again (using the cluster as one object). It then creates a cluster from the next closest pair, recalculates the distance measure, and so on, until all cards have been included. We used the **av-**

²<https://www.r-project.org/>

average linkage method for calculating the distance between clusters where the distance between clusters is determined by the average distance between objects in the clusters. For the purpose of this study, we use average linkage as it compromises options between the previous two methods and data might be better represented. The resulting **dendrograms** of women who have experienced miscarriage are shown in Figure 5.3, while the **dendrograms** of women who have not experienced miscarriage are shown in Figure 5.4. We used the OptimalWorkshop web based service for classifying the categories' label. from our analysis of the card sorting provide a fine-grained analysis of how women perceive support and this will influence the detailed design of the App.

5.3 Findings and Discussion

5.3.1 Categories' Labels

The results of our study, which applies card sorting in the design process to the construction of women who have miscarried and their oriented perception of support for a prototype of a mobile application (presented in Chapter 6) centered around the topic of “Miscarriage“, make clear the benefits of involving women who have not experienced miscarriage in the process. Participants from both groups provided labels for the set of cards they created. Tables 5.3 and 5.4 show the most common term, some variants, and the standardised term the thesis author used. The participants who have experienced miscarriage created a total of (N=238) categories; we identified thirteen standardised label categories in all. These thirteen categories are: *Coping, Feelings, Information, Miscarriage, Need, People, Pregnancy, Reaching Out, Recovery, Self-Care, Support, Time, and Things did not do* (c.f. Table 5.3). On the other hand, the participants who have not experienced miscarriage created a total of (N=160) categories, but we identified nine categories in all. These nine categories are: *Coping, Information, Medical, Miscarriage, Need, People, Pregnancy, Self Help and Support* (c.f. Table 5.4). Seeing the difference in the categories' label giving us, as a designers, the correct way of glasses to better understand the women perception towards support.

The exploratory CLA can lead to overall adequate conclusions: participant categories are generalised and summarised. Therefore, if participant “A“ labels one of her categories “Human support“, and participant “B“ labels one of her categories “Medical support“, these two labels indicate there might be an overall category about *Support* in the App design.

Table 5.3: Standardise terms of participants who have experienced miscarriage

Most Common Term	Variants	Standardised Term
Coping	<i>"supportive steps", "Things I do to keep my mind off of problems", "The way which I dealt with it on my own", "Distraction techniques (avoiding thinking about it)", "Things I do to help myself heal", "Coping mechanisms", "hobbies", "private ceremonies", "online activity", "daily activity", "What i can do to try and take my mind off", "Dealing with it alone", "Distractions", "Coping Methods", "self help/coping ideas".</i>	Coping
Feelings	<i>"Feelings", "Dealing with grief privately", "Emotions", "Devastated", "my feelings/emotions", "How I feel", "Dealing with feelings".</i>	Feelings
Information	<i>"Evidence-Based Information", "Getting the type of information I needed", "Resources", "Informative", "access of information", "Seeking information", "Immediate medical information", "If I wanted more information to understand better what had happened and why", "getting information without being judged", "Medical information", "Med", "Research", "Info", "Information", "Medical Knowledge I need", "Who I gather medical information from", "How I seek help or information".</i>	Information
Miscarriage	<i>"Loosing the baby", "Miscarriage starts", "Miscarriage", "The diagnosis/miscarriage", "During the miscarriage", "first finding out about the miscarriage", "later on after miscarriage", "After miscarriage", "Bad News".</i>	Miscarriage
Need	<i>"Things I wished to get", "Needs", "Want", "what I want", "needing help with", "If I were at crisis point", "What I need help with", "What I need when I am pregnant", "What I want and do after miscarriage", "need support immediately after finding out about miscarriage", "Things I needed when I miscarried", "What I would like in event of miscarriage", "Needing help", "What I need help with", "Most important thing".</i>	Need
People	<i>"Supporters", "people who can give support and care", "Professionals", "Family & friends", "People I turned to for emotional support", "People I did not tell/seek support from", "People around me", "people that can help", "People", "who to talk to", "Drs", "Who I would talk to", "I got the support from", "People who don't understand and try to say helpful things, but they aren't", "telling people later on about miscarriage", "Friends", "Telling people", "People I'd like information from", "People who will not know", "Family", "People to help me", "Who I Tell", "people involved", "People who could support me", "People who help", "People who could help".</i>	People

Pregnant	<i>"Being Pregnant", "Pregnancy & health", "Initially pregnant", "Finding out", "I have not been pregnant since/does not apply", "Things I would like when I am pregnant", "Pregnancy", "Pregnant", "When I am pregnant", "How I deal with pregnancy".</i>	Pregnant
Reaching out	<i>"Access", "Social Media", "Things I never used or reached out to", "communication to people", "reaching out to people", "People I reached out to and things I did", "Where u would go for help and support", "Places I went for support and info", "Reaching out", "Connecting with others", "Real world personal connections for support", "How I can try to help others", "Online/remote information and connections".</i>	Reaching Out
Recovery	<i>"Recovery", "Healing", "When I recover from the miscarriage", "What I did to help recover", "Managing", "Important when recovering and regrouping after a miscarriage", "Therapies".</i>	Recovery
Self-Care	<i>"Self-Care", "self help", "personal care", "Self-care techniques (including thinking about it)", "time for me", "Personal", "Relax", "Myself", "Personal-I", "Ways I look after myself", "Things I can do to help myself", "Self care activities", "How I take care of myself".</i>	Self-Care
Support	<i>"Emotional Support", "Human Support", "Health Support" "Computer Support", "support network", "Practical Support", "Supports", "Helping", "Help", "social support", "How I would of liked to ongoing receive support", "Support I'd have liked", "How I seek help", online help", "support in the home", "Support I may have liked to have", "medical support", "professional support", "No support from professionals", "Phone / Online support", "Support I had when I miscarried, "other support materials", "other ways to help", "various support"</i>	Support
Time	<i>"Steps", "times when I need support", "The beginning of the end", "Useful times for help", "When I needed people", "Times I most need/needed support", "Important at the time of a miscarriage", "symptoms", "When to get help", "Time or moments when I was happy but needed support and care", "Time or moments when I was sad and needed support or care", "How I track".</i>	Time
Things did not do	<i>"Things didn't work with me", "Not Helpful", "Not easy with other children", "Non essential", "Things i wouldn't do", "Things I did not do", "Not for me", "N/A to me", "Things I do not need or use", "What I didn't do", "Things I would never do", "Not relevant", "Things that I didn't use/didn't help".</i>	Things did not do

Table 5.4: Standardise terms of participants who have **not** experience miscarriage

Most Common Term	Variants	Standardised Term
Cope	<i>"what I am do after", "Social Support/Coping", "things I can do to start to help me", "Dealing/coping with miscarriage", "the things that could help with my mind and well-being afterwards", "Ways to cope", "Things that could be done to feel better afterwards", "Things to do to cope", "Things you might do to help yourself cope during or after a miscarriage".</i>	Coping
Information	<i>"Information", "Finding out information", "Information and Support", "find information", "Things to know about", "Information", "Advise", "Situations where you might want to seek information or advice about miscarriage", "Information/Resources", "Resources to access", "Access to Information", "Access to Services", "Easy access help".</i>	Information
Medical	<i>"Medical Support", "Medical-I", "Medical", "Medical Issues".</i>	Medical
Miscarriage	<i>"Miscarriage", "After Miscarriage", "Things that would make me worry about potential miscarriage either now or in the future", "Post-miscarriage", "Actual miscarriage", "I am going to miscarry", "I'm have miscarried", "Discovering Miscarriage", "Recovering From Miscarriage", "Anticipating Miscarriage", "Going Through Miscarriage", "Beginning of the end", "The end".</i>	Miscarriage
Need	<i>"Needs", "What support is needed", "Support needed", "what i want", "When support is needed", "when i need support", "Things you want during or after a miscarriage", "Needing mental support".</i>	Need
People	<i>"People who can support", "People who care", "the people", "Friends and family", "Professionals who can help", "Professionals", "Helpful people", "People to talk to", "People who can support me", "People that could provide support", "People", "people to get support from", "People who can give support", "People who could support you during or after a miscarriage", "Small things people can do", "Other people".</i>	People
Pregnancy	<i>"Pregnancy", "pregnants reveal", "Pregnant", "Throughout pregnancy", "I'm pregnant", "I am still pregnant", "Going Through Pregnancy", "Anticipating Pregnancy", "the beginning".</i>	Pregnancy

Self Help	"Self help", "Self Help Strategies", "Ways to support myself independently", "Seeking help alone and without telling anyone personally", "Self Confidence", "Self care", "Taking care".	Self Help
Support	"Support Network", "Support like to have", "Help" "support I've had", "Support not worked", "Ways to gain support", "Support that's worked for me", "Seeking professional help and support from those who have experienced the same or helped others through it", "Seeking support from friends and family", "The support that I would like to have", "The support that I want to do", "Practical Help", "Ways I can get help", "Support Networks", "Mental support", "Timely help", "Physical support", "useful help", "help with miscarriage", "How support can be given ideally", "Help", "Immediate help", "Practical help", "Support".	Support

While women who have experienced miscarriage use terms such as **Feelings, Reaching out, Recovery, Time, and Things did not do**, none of these terms were used by the other group. These standardised labels revealed that the cards were often grouped based on their experience with miscarriage (e.g., women who have experience versus women who have not), and these participants tended to group cards according to their miscarriage experience and the support provided or requested during their experience (e.g., I reach out to a phone helpline). For example, label **Feelings** could reflect on the importance for the design of the prototype to present an information on how to deal with feelings during and following miscarriage, or the prototype design might help connect women with people who could provide compassionate support. This is consistent with results found in Chapter 4, where women who have miscarried felt it was hard to understand their feelings following miscarriage and described a clear need for information and support to help them understand their feelings.

Moreover, the **Reaching out** label would reflect on the women's practice reported in Chapter 3 and Chapter 4 during and following miscarriage as an attempt to reach out to resources or people who could provide social support by using various online and offline means. Particularly, participants who have miscarriage experience grouped cards (e.g., I email people, I talk to people on Facebook, I write letters, I reach out by phone) in the **Reaching out** category. This is provide an insight into the women who have miscarried perception toward support and empathises into a need to design the

app in a way that help those to easily reach out to their needs and support.

The differences we observed in the way the participants of both groups labeled these categories suggests that women who have miscarried interpret the concepts they are dealing with on the basis of their personal experience with miscarriage. Those differences between both groups have the potential to influence design of the App. For example, the standardised label **Recovery** would indicate a need to present contents in the app about how to help recover, what are the tips that could help recovery, or where to go to help recover. **Self-Care** is another example for the information domain that participants would love to see in the app content, with information about how to take care of themselves and who within the miscarriage circle of care could help in that. Moreover, category **Time** suggests that App design should be proactively structured to match possible timelines of miscarriage, so that it becomes easier for women who are experiencing or have experienced miscarriage to access the provided social support in timely manner based on where they are in their miscarriage timeline. Our hypothesis is that these categories' labels match the perception of women with miscarriage experience better than those proposed by women who have not experienced miscarriage. The validity of this hypothesis will be tested by a formal usability experiment of the identified categories and labels as reported in Chapter 7. Another interesting observation was that one of the labels given in the card sorting experiment was **Things did not do** by women who have experienced miscarriage. This is particularly interesting as the phrase **Things did not do** itself indicates that not every cards presented while they were sorting fit everyone's experience with miscarriage, and there should be a variety of offered options for information and support, or it might reflect on things that women did not do, such as things they just did not think of, things that were prevented, things that the care system did not do, or could have done in a proper way, but this is a claim deserving of further study. Further, our observations suggest that one of the reasons for differences in grouping lies in the use of different mental representations. Some of the differences can be explained by differences in the miscarriage experience itself. Our study reported in Chapter 3 clearly identified that miscarriage experiences varied between participants and each participant reacted differently too. These differences show that tailoring based on a specific target group is needed. However, all participants from both groups showed a need for certain standard categories, most of which are already present in Tables 5.3. For example, **Support** labeled to address support availability and coping strategies is a uniform need, and a category that indicates how

miscarriage affects women who have miscarried also surfaced from categories' labels analysis. When designing applications for homogeneous groups, gaining insight into their mental models is important to be able to attune the design to these needs [LeRouge et al., 2013].

5.3.2 Hierarchical Cluster

Card sort results were analysed according to a HCA performed on the collection of cards (clusters) that every participant created. In this analysis, patterns of cards that are related to each other according to participants' mental models are identified by analysing how often they are placed together in one cluster. The dendrograms presented in Figures 5.3 and 5.4 shows the complete list of cards that were presented to participants for sorting. Then, brackets are drawn between cards, based on the degree to which participants grouped the cards together. Cards that are the most frequently grouped together are placed next to each other vertically, with a line joining them to indicate the association between the cards.

Some aspect of hierarchical cluster in this study can be mapped onto at least one of the five themes established in the co-design workshop. For example, the cards of **Time to get support** category (e.g., When I found out about miscarriage) (c.f. Table 5.2) are placed together vertically with people from the formal care networks as presented in Figure 5.3. This could be mapped into the aspect discussed previously in Chapter 4, focused on the need to connect women to an authoritative source(c.f. Section 4.3.1). **The App should be designed in a way which support in connecting women to their formal care network where social support can be presented in a timely manner during the early pregnancy, so that it is readily available, and can be consulted as needed across the rest of the miscarriage timeline.**

A focus on HCA offers the detailed design of the App by providing insight into what cards' contents are related to each other, in the participant's view. In this study, cluster analysis rendered quite clear clusters with lineal agreement between women who have experience miscarriage clustering. However, visualising the clusters in a dendrograms using small distance for cards placed together by most participants enables researchers to identify overlap between categories when cards are placed with cards from another category but still less than their own category. For example, participants grouped the card *Access in Safe way* with cards from another category **Techniques used to get support** category, as shown in Figure 5.3. Unlike other group who grouped the cards

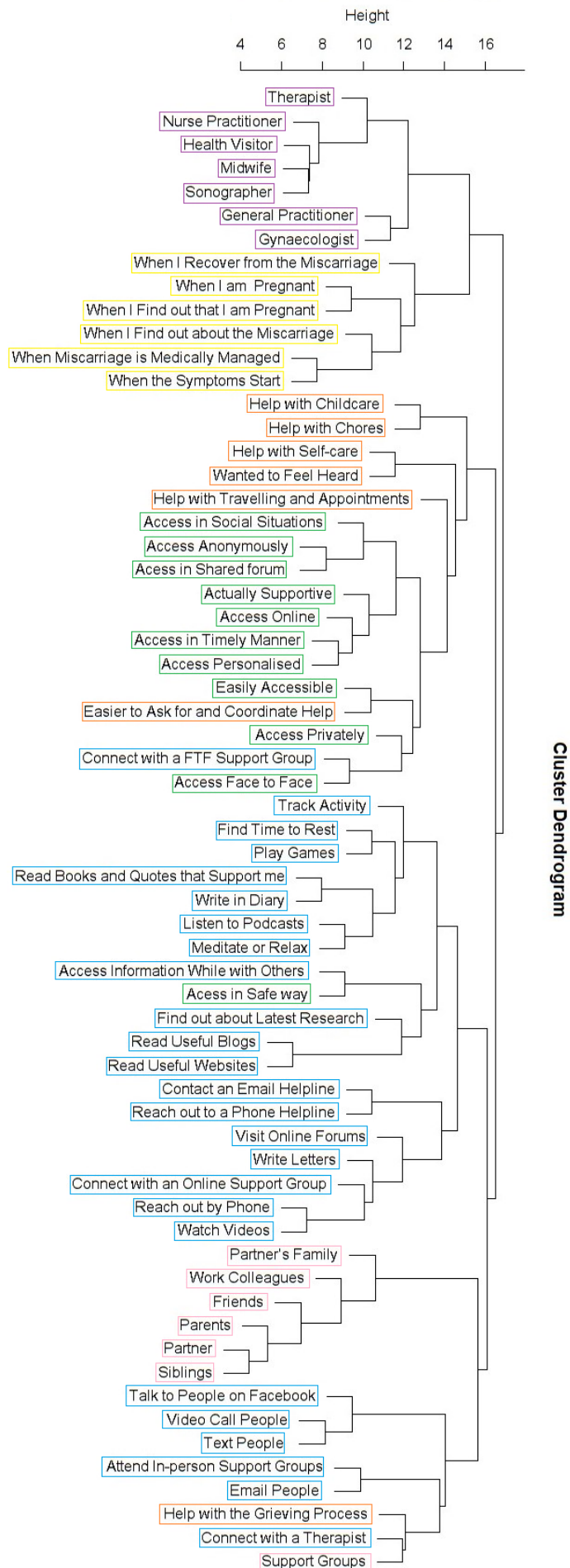


Figure 5.3: HCA for participants with miscarriage experience

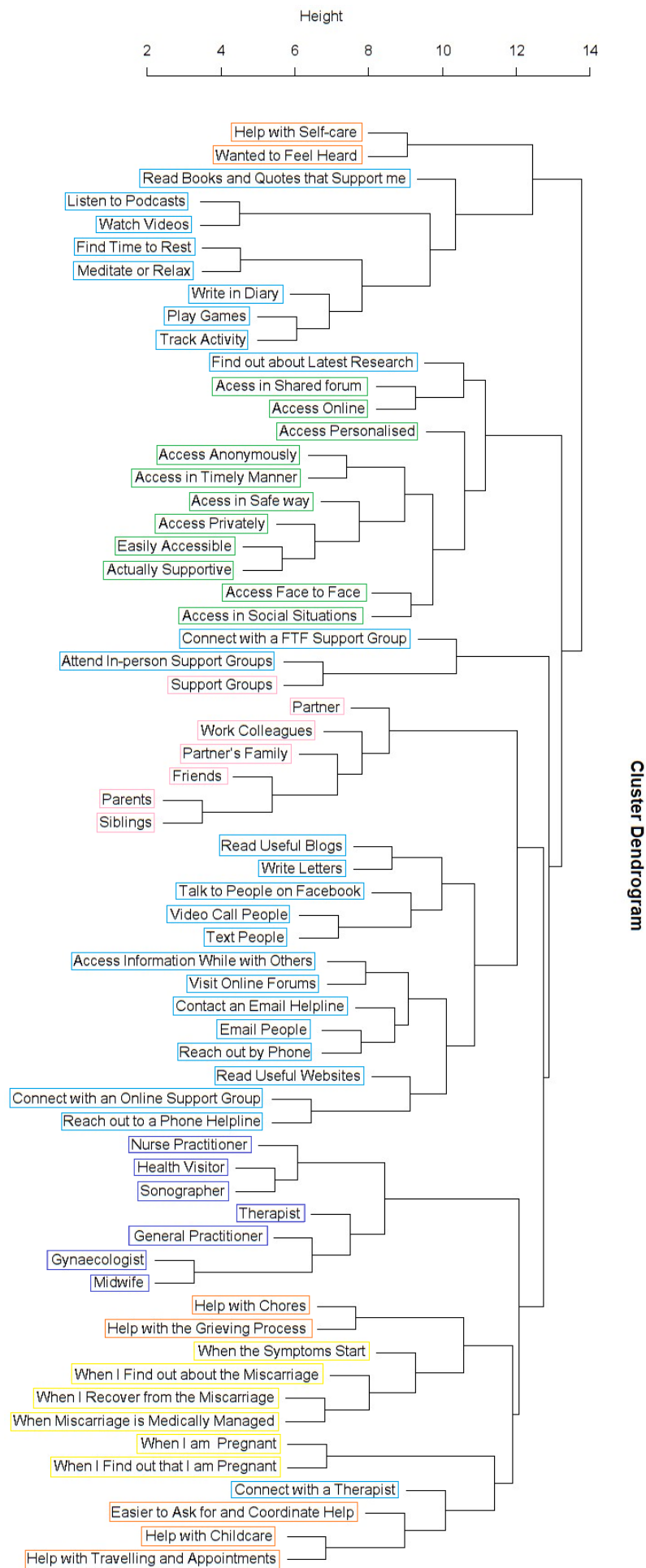


Figure 5.4: HCA for participants without miscarriage experience

of **Techniques used to get support** category infrequently in a group and thus have a high distance score (they are farther apart). Moreover, although cards refer to the informal care network were placed in a closer cluster by women who have miscarried, *Support Groups* card were grouped by a lot of participants together with cards from **Techniques used to get support**. Participants who have not experienced miscarriage, however, tended to group *Support Groups* with another category's cards conceptually and to be influenced by common words found in cards titles (e.g., *Attend in-person support group* and *Connect with Face-to-Face support group*), as shown Figure 5.4. Further, *Help with the Grieving Process* card has been placed with *Connect with Therapist* and *Support Groups* in a group by lots of participants, as shown in Figure 5.3 have a vertically low distance score. This findings could be mapped onto an aspect discussed previously in Chapter 4, focused on connecting women in such support services that help women understand a range of complex feelings and grieving process following miscarriage (c.f. Section 4.3.4). **The App should be designed in a way that connect women with such emotional support services privately, or providing a lot more specific information and support that helps women with the grieving process.** In addition, the cards *Easily Accessible*, *Easier to Ask and Coordinate for Help*, *Access Privately*, *Connect with Face-to-Face Support Group*, and *Access Face-to-Face* were all grouped together within a group by lot of participants who have miscarried, and have a vertically low distance score as shown in Figure 5.3. This findings could be mapped onto an aspect discussed previously in Chapters 3 and 4 highlighting difficulties in finding out the face-to-face support group, and a need for the an easy access to find an appropriate local support. **The App should be designed in a way which support women who have miscarried to easily find an appropriate local peer support which consider as key for healing process.**

In this study, hierarchical cluster analysis methods demonstrate that participants who have miscarried generate more homogeneous clusters than participants who have not. This illustrates that the knowledge of participants who have miscarried might be influenced by their miscarriage experience. Therefore, the mental model or the participants who have miscarriage experience is more in agreement with a homogeneous clustering than a heterogeneous one as a result of having a group of participants who are sharing the miscarriage experience homogeneously as a group. The more homogeneous clustering, the more sharing of the same experience, and more understanding of miscarriage knowledge. This illustrates that the knowledge of the miscarriage topic for

women who have not experienced miscarriage probably varies more and is influenced by their own knowledge about the topic. This also support the aspect discussed previously in Chapter 4, focused on the lack of knowledge of people around the topic of miscarriage and the need to educate people and raise awareness in the society to have better perception towards the support needed throughout miscarriage journey (c.f. Section 4.3.5). **The App should be designed in a way that support the care networks to get educated and understand miscarriage circumstances by providing such guidance without putting for the onus on the women experiencing miscarriage.**

5.4 Limitations and Future Work

The main limitations of this study are a lack of representativeness; for reasons of cost, we were unable to ensure that the sample was representative of people who miscarry in the UK. It also used categories of cards that were derived by researchers who had not experienced miscarriage themselves from the ARC study reported in Chapter 3. A card sorting study where participants were able to write their own cards or rename / rephrase existing cards might produce different results. Finally, we did not compare the models of people with miscarriage experience who had different reproductive histories.

Whilst these are potential limitations, we also argue that our findings contributes to identifying meaningful patterns that are symptomatic of underlying mental models of women who have miscarried. It assists to introduce the design of ideas and taxonomies for interface design for this specific target populations. Thus, we believe that, despite the limitations, there is value in the findings; particularly the findings where we were able to show the differences between the categories' label, and the homogeneous clustering of women with miscarriage experience and who have not. This understanding of other group mental models allows for a better understanding of how we might design better for a specific target group.

There are several ways in which future work could extend or further validate the work done in this chapter. It could be valuable to consider conducting a formative research study to inform the design of information architecture of a prototype of mobile application that designed in Chapter 6 for supporting women who have experienced miscarriage. Further, since we also obtained data from women who have not experienced miscarriage, which helped capture differences between those who have experienced miscarriage and those who have not, those data might be useful in future work on pre-

senting miscarriage related information to members of the miscarriage circle of care who have not experienced a miscarriage themselves.

5.5 Summary

The value of the card sorting method stretches beyond the design phase: it provides insight into users' mental models to help design a system with a more sophisticated and more accurate model of users. The results of this study showed that involving prospective users in the design can capture users' underlying perceptions of the support within the the App. The resulting standardised labels and dendrograms can be influenced the App's detailed design to be more user-friendly, because its design is a closer fit to user's mental model. Additionally, the simple satisfaction of incorporating both groups' points of view had a tremendous impact on the generation of ideas during the design of the prototype, as discussed in next chapter. Thus, this helped us to decide on the structure of the interface design of the prototype as discussed in Chapter 6, although this needs further investigation, as presented in Chapter 7.

“ Design is a funny word. Some people think design means how it looks. But of course, if you dig deeper, it’s really how it works. “

Steve Jobs

6

Prototype Architecture and Design

6.1 Introduction

Socio-technical systems (STS) design and various technologies have been introduced to support womens’ health in different settings, including pregnancy. These STS designs include self-monitoring [Thomas and Lupton, 2016, Smith et al., 2017, Costa Figueiredo et al., 2017], information sharing [Bjelke et al., 2016, Fourney et al., 2015] and mechanisms for social support [Morris, 2014, Gui et al., 2017]. Indeed, Peyton et al. [2014] suggest designing mobile application for pregnancy, where pregnant women can choose which members of their social circle they want to give access to their tracking, and that allows people to tailor the app to their unique pregnancy experience. We suspect this is because many of the mobile health applications available commercially are designed to target pregnant women. The equivalent applications for miscarriage simply do not exist.

In this research, and through the literature, we found that women experiencing a miscarriage continue to utilise technology for support when other options fail them. While

technology can link women to online resources, sites and communities that provide much of the needed support, it cannot plug the support gap left by the reality of miscarriage social support delivery discussed in this research. To illustrate, interventions such as internet-based psychotherapy [Kersting et al., 2011] and online forums [Betts et al., 2014] might incorporate some of the design goals mentioned in this chapter, women are most likely to use those interventions after the miscarriage is happened. Moreover, Not Alone [Andalibi et al., 2018] create a safe space for women to reach out to others and discuss their feelings openly after miscarriage that protects against stigma. However, given the strong preferences for social support sources evidenced in Chapters 3, Section 3.3 and Chapter 4, Section 4.3, it is important to design solutions that allow women to choose their desired level and modality of interaction (e.g., reading, messaging, calling). Moreover, our exploration of the social support needs and dimensions of women who have miscarried demonstrated the stigma nature of the miscarriage experience for sharing their experiences within their care network. Stigma and social isolation were identified as some of the major challenges in the lives of women who have experienced miscarriage and is exacerbated by the lack of adequate communication channels with their formal and informal care networks. The existing communication techniques are not as effective as they should be at reducing the feelings of isolation for women who are already challenged by the special needs of their miscarriage experience. Therefore, STS might promote collaboration with Peer Advisors and the existing care networks.

In this chapter, we introduce and discuss the Design Goals (DG) of the *Journey* app in response to the outcomes of the ARC exploratory study (c.f. Chapter 3) and design engagement activities (c.f. Chapters 4 and 5), along with previously applied studies that inspired the different features of the tool. The *Journey* app design is presented, with personas, scenarios and design prototype along with hierarchical task analysis architecture for different tasks. Finally, we conclude this chapter with a summary of the prototype design contribution. Specifically, this chapter together with Chapters 4 and 5 are aim to answer the second research question listed in Chapter 1, Section 1.1.

6.2 Design Rationale

Based on the findings from the ARC (c.f. Chapters 3), co-design workshops carried out (c.f. Chapter 4), and online card sorting results collected (c.f. Chapter 5), we devel-

oped six DG for mobile application to support the needs of the social support of miscarriage and promote the Miscarriage Circle of Care Model (MCCM). In this section, we describe the specific design principles of the *Journey* prototype. These include: Streamlined access to social support (DG1); Integrating into pregnancy system (DG2); Healthcare and trustworthy provision (DG3); Connecting to peers' experiences and stories (DG4); Proactively educate society about miscarriage (DG5); and Lightweight communication channel (DG6).

Based on the findings of the previous design phase, we have noted the various forms of support required in the context of miscarriage. In this respect, we recognise the need to establish various support channels in the designed solution, enabling the MCCM. These communication channels can facilitate the informal care network's access to guidance and reassurance to remain educated about miscarriage services. In addition, these channels can reduce the stigma surrounding the topic of miscarriage, which requires communicating and educating other care networks by allowing the women to share their experiences openly. *Journey* might be beneficial, especially in shifting burdens of support and communication while allowing the women to cope more effectively.

Therefore, we introduce here the prototype of the *Journey* app, which is a socio-technical tool that has three purposes:

1. help women who have miscarried meet their social support needs;
2. help people in the miscarriage circle of care to provide better support to women who have miscarried;
3. provide a library of relevant information, resources and support. Some of these will be specific to the country and healthcare context (insurance provider, hospital, or obstetrician/gynaecologist network in the US; NHS trust in the UK).

Table 6.1: DG1. Streamlined access to social support

Design Rationale	Design Origin
<p>In practice, the women were familiar with finding social support and interaction with their care network using smartphones, which they found practical to use whenever the support is needed. However, the women cannot predict where or when the actual needed support will start. Therefore, mobility and usability are key design considerations for findings about social support technology in such settings. As a result, we suggest building support intervention that can be easily accessed for the women who have miscarried. If the thesis author endeavor to figure out this intervention with women who have experienced miscarriage, smartphone platforms are probably the best options. Therefore, we suggest combining and re-appropriating the features of selective technologies and leveraging the womens' own smartphones and past experiences of accessing the social support. Consequently, the burden of finding or accessing social support will be reduced, which is considered a requirement to promote the adoption of technology [Liu et al., 2011].</p>	<p>In the ARC exploratory study reported in Chapter 3, all participants had a smartphone and use it on a daily basis, and this was the biggest technology use pattern they had in common (c.f. Section 3.2.2, Table 3.1). In addition, with our attempt to understand the mental model of women who have miscarried in Chapter 5, we had noted that (94%) of the group of women who experienced miscarriage utilised a smartphone on a daily basis (c.f. Section 5.2.2, Table 5.1). In the co-design workshops reported in Chapter 4, smartphones were often chosen by the women when seeking social support or communicating with their care network due to their mobility and availability (c.f. Section 4.3.7). In fact, 4 out of 5 women who participated in these workshops relied on their smartphone to access internet resources to find information related to miscarriage and in communicating their social support needs to their care network. (c.f. Section 4.3.7).</p>

Table 6.2: DG2. Integrating into pregnancy system

Design Rationale	Design Origin
<p>Accessing social support earlier on is a critical element in experiences of women who miscarried in assisting them understanding their decision, reactions and relevant triggers. Most uncomplicated pregnancies follow a clear timeline with plenty of social support resources. However, this structure is ripped away once the miscarriage occurs, and replaced with general after care for wellbeing advice [White and Bouvier, 2005, Catlin, 2018]. A drastic shift like this leaves many women with questions such as the reason behind the miscarriage. There are resources such as websites, leaflets and books [Boynton, 2018]; however, finding and accessing them at the right time is difficult. While not all miscarriage social support can be presented earlier in pregnancy, general concepts may be shared during the beginning of pregnancy. Therefore, women can be aware of this social support and explore at their own pace. Ideally, technology should be designed in a way that focuses on pregnancy and may add a section dedicated to include miscarriage support or direct access to trusted resources, so that it becomes easier to know what to expect, prepared for the next steps, and access it when they are ready to proceed in a time frame that suits their needs. However, creating such a guide for miscarriage might be considerably complex due to the diversity of miscarriage experiences. For example, some women might experience symptoms and pass by the Trigger Event stage, while others might find out that they have miscarried during an ultrasound appointment.</p>	<p>As we saw in our finding of the co-design workshops reported in Section 4.3.1, participants wanted miscarriage social support to be presented earlier on. In particular, they needed reassurance and to feel prepared for the next steps. In our attempt to understand the mental model of miscarriage in the card sorting study reported in Chapter 5, we identified a category labeled <i>Time</i> suggests that App design should be proactively structured to match possible timelines of miscarriage - including pregnancy-, so that it becomes easier for women who are experiencing or have experienced miscarriage to access the provided social support earlier on and in timely manner based on where they are in their miscarriage timeline (c.f. Section 5.3.1).</p>

Table 6.3: DG3. Health Care and trustworthy provision

Design Rationale	Design Origin
<p>Receiving trusted healthcare provision information is considered a central element for receiving appropriate social support. Trusted resources are among the main concerns surrounding the womens' social support needs in various contexts. While participants wanted to be directed to resources by their trustworthy sources (e.g., formal care network), they discussed the negative experience of finding information out online for their own answers by themselves. Moreover, despite the benefits of health websites and online forums, these online technologies bring with them issues of trust and reliable information. Accordingly, such tools could be designed to provide social support by accredited healthcare providers, or at least tools that are certified by the healthcare providers to increase the information's reliability, and the reliability of provided social support and care throughout the entire miscarriage process. While the designed technology might be provided by healthcare organisation, there should be a coordination between healthcare providers (e.g., NHS) and the Peer Advisors (e.g., Miscarriage Association). This should include engagement with each other to ideate better ways of reaching out to women who have experienced miscarriage, as well as enabling and optimising their access to social support and care within the health organisations and other services.</p>	<p>In ARC contextual study findings (c.f. Chapter 3), the formal care network emerged as a highly trusted and preferred source of informational support, and providing appropriate informational support by the formal care network can make a substantial difference to a woman's ability to cope with miscarriage (c.f. Section 3.3.2.1). In the co-design workshops study (c.f. Section 4.3.2), the participants' concerns about the trust of the information pointed to the need for them to have full access to healthcare and trustworthy provision channels. While women were gathering informational support, they reluctant to take random information into consideration, and they sought healthcare provision (c.f. Section 4.3.7). In the card sorting study findings (c.f. Section 5.3.2), hierarchical cluster analysis showed that Time to get support pattern cards were frequently grouped together with cards of the formal care network in one cluster (c.f. Figure 5.3), which in turn reflect in that participants desired to have more access to their formal care networks throughout their experience.</p>

Table 6.4: DG4. Connecting to peers' experiences and stories

Design Rationale	Design Origin
<p>Women benefited greatly from the similar experiences of others (i.e., women who have experienced miscarriage). Therefore, when designing a STS for women who have miscarried, it is worth considering that the system might include a choice for users to be connected with similar others (i.e., other women who have experienced miscarriage). Such a system might allow women to connect with those who are knowledgeable to provide compassionate services to discuss physical and emotional recovery and link them up with trustworthy offline and online support services, including support group options. We suggest building on the support intervention by implementing a concept of coordination between the formal care network and Peer Advisors; for example, the women would be signposted to a local in-person support group or online community [Andersson and Monin, 2018, Penrod et al., 1995]. Connecting with people in similar situations would not only improve their emotional states but provide a space to learn from each other. Furthermore, providing sorted stories of similar womens' situations on a miscarriage timeline may also be beneficial to women with corresponding situations in anticipating possible future events or triggering feelings; we noticed women feel less frustrated if events unfold along predictable lines. Similar to Andalibi et al. [2018]'s Not Alone system, the system should connect women to others who share similar experiences, so that they can seek emotional and social support at a level of disclosure with which they are comfortable. However, this connection needs to be at the discretion of the inexperienced women regarding how they prefer to interact (e.g., only wanting to hear the other's story and not being ready to talk about their own) [Andalibi and Forte, 2018]. The system should provide a safe space to explore and share their own story anonymously [Kitson et al., 2013]. Since hearing other womens' experience and stories helped participants reframe their experience without the self-blame; the system should allow women to share as much or as little as they like, and to read other womens' stories before disclosing their own particularly when miscarriage is still recent.</p>	<p>As discussed in the ARC study (c.f. Sections 3.3.2.2, 3.3.2.3, and 3.3.2.4), participants noted that women with similar experiences were particularly important to help participants cope after miscarriage, and were shown to provide an appropriate social support. According to ARC study findings (c.f. Section 3.3.2), two coping strategies have been shown to be helpful, which are allowing the women to talk openly about their feelings and thoughts, and encouraging contact with other women with similar experience; those strategies also have been reported previously [Andalibi and Forte, 2018, Bellhouse et al., 2018b]. In particular, the question of dealing with a range of emotions after miscarriage emerged as an important issue during the recovery phase of the miscarriage journey (c.f. Section 4.3.4). In the co-design workshops study (c.f. Section 4.3.3), women who participated currently use platforms such as websites or online forums to read the stories of other women who have miscarried. In the card sorting study findings (c.f. Section 5.3.2), hierarchical cluster analysis showed that women who have miscarried wanted the peer support to be easily accessible through connecting women with other women with similar experiences privately and at the right time. Perhaps the most important function of STSs for miscarriage is contact with others who have had similar experiences.</p>

Table 6.5: DG5. Proactively educate womens' network about miscarriage

Design Rationale	Design Origin
<p>Participants reported unwanted responses from their informal care network, including the belittlement of their miscarriage, thus they became more hesitant to contact their informal care network. The system should allow the women who have miscarried to notify their entire network about the type of support that they need. This notification can be done through sending a text message or email or through providing the care network an access to the same system or different version of the same system. However, in providing the whole network access to the system, further investigation is required as they are a category of user that needs to be considered more explicitly in the design. The system would allow the women to decide what form the social support should take, responding to their support needs and fitting each woman's circumstances. For example, women who have miscarried may notify their network for the nurturant support needed and appropriate reactions to their miscarriage (e.g., the phrase to say and how to say it), by providing information and guidelines to inform them of how to provide effective support and how to navigate their own discomfort. Thus, the system perhaps can help make the miscarriage less of an embarrassment, so people can get the facts and understand the feelings associated with miscarriage.</p>	<p>Based on the ARC (c.f. Sections 3.3.2.2 and 3.3.2.3) and co-design workshop findings (c.f. Section 4.3.5), participants comprehensively discussed and reiterated the need to train the formal care network and educate the informal care network and raise awareness in order to help the society understand and recognise their loss. In the card sorting study, where we involved women who have not experienced miscarriage in the study, findings demonstrate that those women generate more heterogeneously clusters and groups created based on labels (c.f. Section 5.3.2, Figure 5.3). This illustrates that the people who have not experienced miscarriage are not sharing similar knowledge about miscarriage, and there is an overall lacking understanding of miscarriage experience; hence, this reflects a need to educate people and raise awareness in the society about miscarriage.</p>

Table 6.6: DG6. Lightweight communication channel

Design Rationale	Design Origin
<p>Our study also identified the different communication practices, with multiple formal and informal care networks using different digital applications. The women looked for support from the formal care network or shared their experiences with their informal care networks. Previous digital solutions have focused on internet-based psychotherapy programmes [Kersting et al., 2011], seeking or posting to internet discussion forums [Betts et al., 2014], or self-disclosure and discussing on social media sites [Andalibi and Forte, 2018]. Recognising the limitations and scarcity of technologies to prompt the social support needs, an asynchronous and lightweight communication and coordination technology should be designed for women, their formal and informal care networks. In this research context, digital solutions should facilitate social support by building on the womens' existing practices of searching and seeking social support. Additionally, any augmentation to the current receiving or requesting support practices must avoid adding burdens onto the womens' routines. The technology should support womens' needs to integrate their different communication practices into one tool. These communications would allow, for example, more connection options with a formal care network, address the challenge of reaching out to in-person meetings, and provide opportunities for the women to engage with their informal care networks to easily share knowledge and educate them. This simple approach is used to enable the women to initiate the process and provide them with the ongoing support and care they need. The support can be synchronous or asynchronous, based on the time that the women need to have access to the system.</p>	<p>Participants in the ARC and co-design workshop studies (c.f. Section 3.3, and Section 4.3.7) provided many examples of how they communicate with their care network through various means. Some of these examples were person to person (e.g., talking to the therapist; meeting with a friend), others were shared with more than one person (e.g., posting on Facebook). Some are synchronous (e.g., a phone call to a midwife) and some asynchronous (e.g., text family). These communication practices demonstrated the various dimensions of the social support needs of the women who have miscarried, including information, emotional, esteem, network and tangible support.</p>

6.3 Prototype Description and Design Scenarios

6.3.1 Design Fiction

Journey is an app that we envisioned for the purpose of this research. We envision that the National Health Services (NHS) has decided to create a new pregnancy support smartphone application to provide a wide range of resources and support on pregnancy with functionality to support women who might be miscarrying. We are designing section functionality for a miscarriage to support women who might be miscarrying. While we envision that the *Journey* is provided by NHS, there should be a coordination between healthcare providers (e.g., NHS) and the Peer Advisors (e.g., Miscarriage Association) to engage with each other to ideate better ways of reaching out to women who have experienced miscarriage, as well as enabling and optimising their access to social support and care within the health organisations and other services.

One of the main elements for women who have experienced miscarriage is to access the social support as early as possible. In *Journey*, this access is facilitated from within the pregnancy application. With the benefit of the *Journey* app, whenever the woman finds out that she is pregnant, and during the early pregnancy stage, she can register with the *Journey* app to support the pregnancy, with functionalities where women can find relevant information and support while she is pregnant. While testing this feature is out of the scope of this research, we have included in the app design the idea of integrating the miscarriage into a pregnancy healthcare system (c.f. Figure 6.1). *Journey* might be used as a library that stores all relevant information, support and services about pregnancy and miscarriage in one place that can be accessed from a mobile phone.

Journey is a STS designed to promote the social support needs for women who have experienced miscarriage and their communication with their care networks, based on the DG discussed in the previous section: (DG1) Streamlined access to Social Support, (DG2) Integrating into Pregnancy System, (DG3) Health Care and Trustworthy Provision, (DG4) Connecting to Others' Experiences and Stories, (DG5) Proactively Educate Society about Miscarriage and (DG6) Lightweight Communication Channel.

While designing the *Journey* app prototype, we make sure that the categories' labels

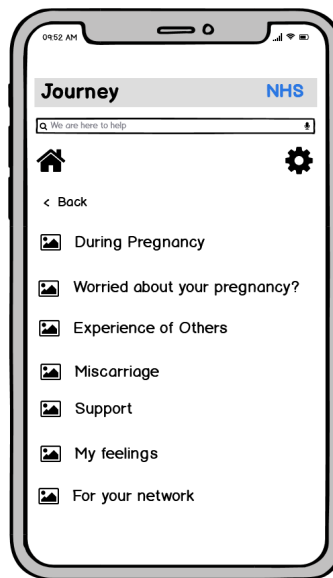


Figure 6.1: Journey app home page

match the perception of women who are experiencing or have experienced miscarriage to provide an accurate mental model of the system. Moreover, we tried to cover almost all the information domain that women with miscarriage experience may try to find, covering almost all derived their perception towards support, as presented in Chapter 5. Additionally, we proactively structured the information architecture (IA) of the prototype Home page to match possible timelines of miscarriage, so that it becomes easier for women who are experiencing or have experienced miscarriage to access the provided social support based on where they are in their miscarriage timeline (c.f. Figure 6.1). Nielsen suggested that user interfaces should “*speak the user’s language*”, involving the existence of adequate mapping between the user’s mental model of the system and the computer’s interface for it [Nielsen, 1992]. Therefore, we made sure to establish the *Journey* app’s contents based on women who have miscarried’ expectations, thus making the resulting design intuitive for them [Bernard, 2000].

The application is to be used by women who have miscarried. The design of the prototype was sketched using Balsamiq¹ to build an interactive wireframe prototype that could be easily reviewed by the participants, either using smartphones or computers.

¹<https://balsamiq.com/>

6.3.2 Scenario, Prototyping and Hierarchical Tasks Analysis Techniques

Information systems and applications designer utilised scenario-based technique as an approach to explicitly envision and document typical user activities throughout the system design and development process. A scenario provides a concrete envisionment of a design solution by specifying the tasks users can or must carry out, but without committing on how the tasks will be carried out or how the system will enable the functionality for those tasks. Scenario often written from a persona's point of view and focuses more on what technology enables than the details of the technology itself [Goodwin, 2011]. A persona is a hypothetical user archetype standing for a group of actual users and documented as a specific individual complete with name, age and any other characteristics pertinent to the design brief. Persona and scenario work well together and both serve to communicate a user's point of view [Martin et al., 2012].

Scenario representations can be elaborated as prototypes, such as through the use of paper and pen and rapid prototyping tools. Prototyping is facilitating building and testing software that embodies design, not concentrating on the design as it is produced. The early prototype might be build to define and verify DG and requirements; the designer can thus observe users' prospective and interacting with such a prototype throughout a formative evaluation of the design [Roos and Hamilton]. Design review and formative evaluation are ancillary activities that must be coordinated with the design itself, and they do not evoke reflection in the context of doing design. However, the process of designing a scenario of use inescapably evokes reflection in the context of design. Moreover, Salustri and Neumann [2018] combined Hierarchical Task Analysis (HTA) and scenarios to help embed human factors in the design process. HTA is a technique that can be used to describe a system's tasks in terms of the goals and sub-goals that the person is trying to achieve and the actions used to achieve them [Pocock et al., 2001].

Therefore, we decide to design scenarios to help us represent the use of a system with a set of women who are experiencing or have experienced miscarriage interaction scenarios that make their use explicit and provide a broader view of the designed STS. In this chapter, we combine using scenarios for the hierarchical task analysis and prototyping to elaborate the components of STS that could implement the envisioned functionality in order to provide the system view. We will use those scenarios as an object during the formative evaluation and design reviews study as described later in Chapter 7.

Table 6.7: Description of the personas designed for this research.

	Persona 1	Persona 2
Name	Emily	Sophei
Age	26	38
Child history	Have one child	No Child
First miscarriage?	Yes	No
Purpose of this case	Communicate informational and network support.	Communicate emotional and esteem support.

To provide a rationale for the choice of personas, we first designed the personas of two women who have experienced miscarriage based on (anonymised) women as identified in the exploratory ARC study in Chapter 3 and series of co-design workshops in Chapter 4. Secondly, since the experience of miscarriage changes the perception of social support as presented in Chapter 5, the personas were designed as a representative of a different miscarriage experience (have differing mental models); one of the personas have already experienced miscarriage journey, the other persona have not, and each were communicating different social support needs. The personas were designed to find personalised social support on their reproductive journey, based on individual experiences and where they are in their timeline. Thirdly, the personas are presented in Table 6.7, with multiple scenarios have introduced for each persona to provide the opportunity for as much breadth of coverage as possible of the issues for women who have miscarried and the different social support settings requested. These scenarios were developed from the earlier scenario work presented in Chapter 4 by adding the perspective of a particular persona and these scenarios are what is used to drive the design. Finally, these personas and scenarios were drafted by the thesis author and then reviewed by her supervisor and one woman who has experienced miscarriage and participated in the ARC study and co-design workshop, to ensure the goals were met and the personas and scenario were realistic. The effectiveness of scenarios might be increased by involving users in creating them to ensure that the real work contexts are represented [Carroll, 1999].

Since the smartphone application (*Journey*) is to be used by women who have miscarried, the use-case scenarios are explained from the side of the women who have

experienced miscarriage as the main initiator of the process of accessing social support. In the following sections, we will introduce the design scenarios, prototype, and HTA of each scenario in relation to the design principles.

6.3.3 Scenario 1: Communication for Informational Support

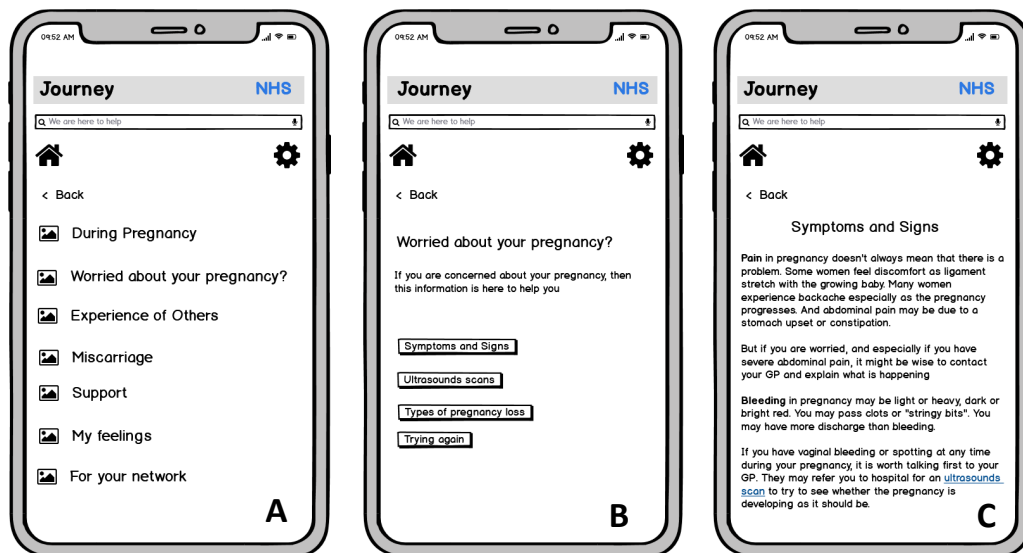


Figure 6.2: Journey app communication for informational support scenario

Emily had missed her period and decided to take a home pregnancy test, which she undertook twice. The result was positive so she called the hospital for an appointment. They gave her an appointment in 12 weeks, and she shared the news of pregnancy with her partner. While she was waiting for her first appointment, she started to experience symptoms, sudden abdomen and back pain and a feeling of discomfort. This was Emily's second pregnancy so she was already registered with the **Journey** mobile app. As she was worried about her symptoms, she opened the **Journey** app to look for more information on what her symptoms might mean.

Emily is worried she may have symptoms of miscarriage. Being familiar with the app from her first pregnancy (DG1, DG2), Emily is comfortable that the app is a safe space for her to read, finding out reliable, accurate, and up-to-date information (DG3) about pregnancy complications (DG2), and finding other people's experiences (DG4). To begin with, she finds the **Journey** app icon on her smartphone screen (DG1) and taps on it to open the app. She notices the "Worried about your pregnancy?" button on the main menu in the home screen (c.f. Figure 6.2A). She taps this button and it brings

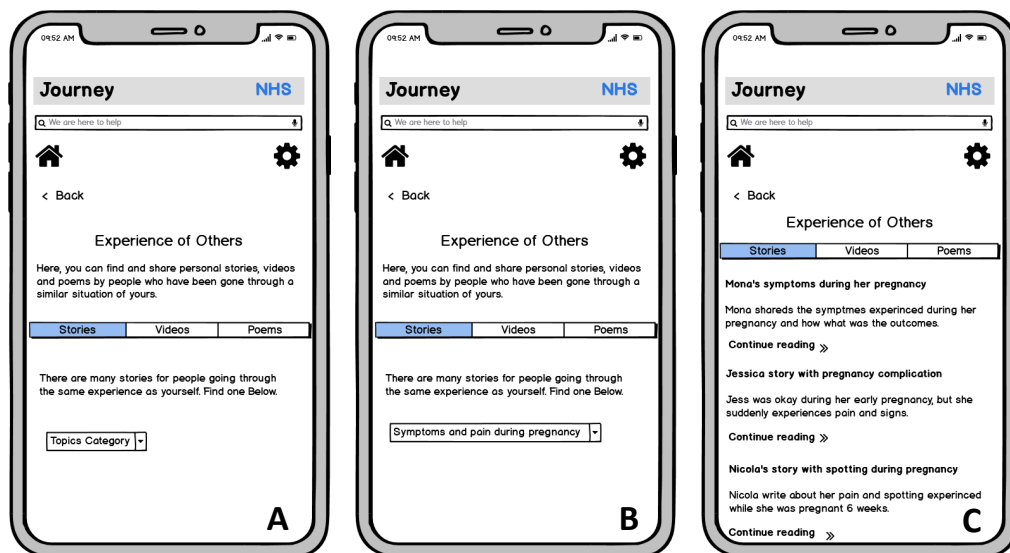


Figure 6.3: Journey app communication for informational support scenario

her to another page where several related information links related to her symptom are displayed (c.f. Figure 6.2B). She starts reading the information through the app and it helps her make sense of what is happening, and what might happen for her pregnancy (DG2, DG3) (c.f. Figure 6.2B and C).

Alternatively, she might would like to know about other women who have had the same symptoms, and different outcomes (DG4). From the "Experience of Other" button, which combines different experiences of people who have been through similar situations, Emily might tap on this button, and this brings her to another page with the options "Stories", "Videos" and "Poems" (DG6). She can select her preferred medium of viewing the information: she might select Written or Vision. She notices the app opened to the Stories tab by default, which helps her locate the topic that she is trying to find information about, and then select from the drop-down menu the topic that she is trying to find other people experience. This drop-down list facilitates Emily to find topics related to symptoms and signs, coping tips, grieving ways, and much more (DG4) (c.f. Figure 6.3A). Once she selects "Symptoms and Signs" (c.f. Figure 6.3B), this takes her to another page with stories from other people who experience symptoms during their pregnancy (c.f. Figure 6.3C). Through using the *Journey* app, Emily was able to find clear, upfront general information of pregnancy complications, including miscarriage of the eventualities in early pregnancy stage, and hence become more informed, prepared and aware of what to expect, and what to do next in the case

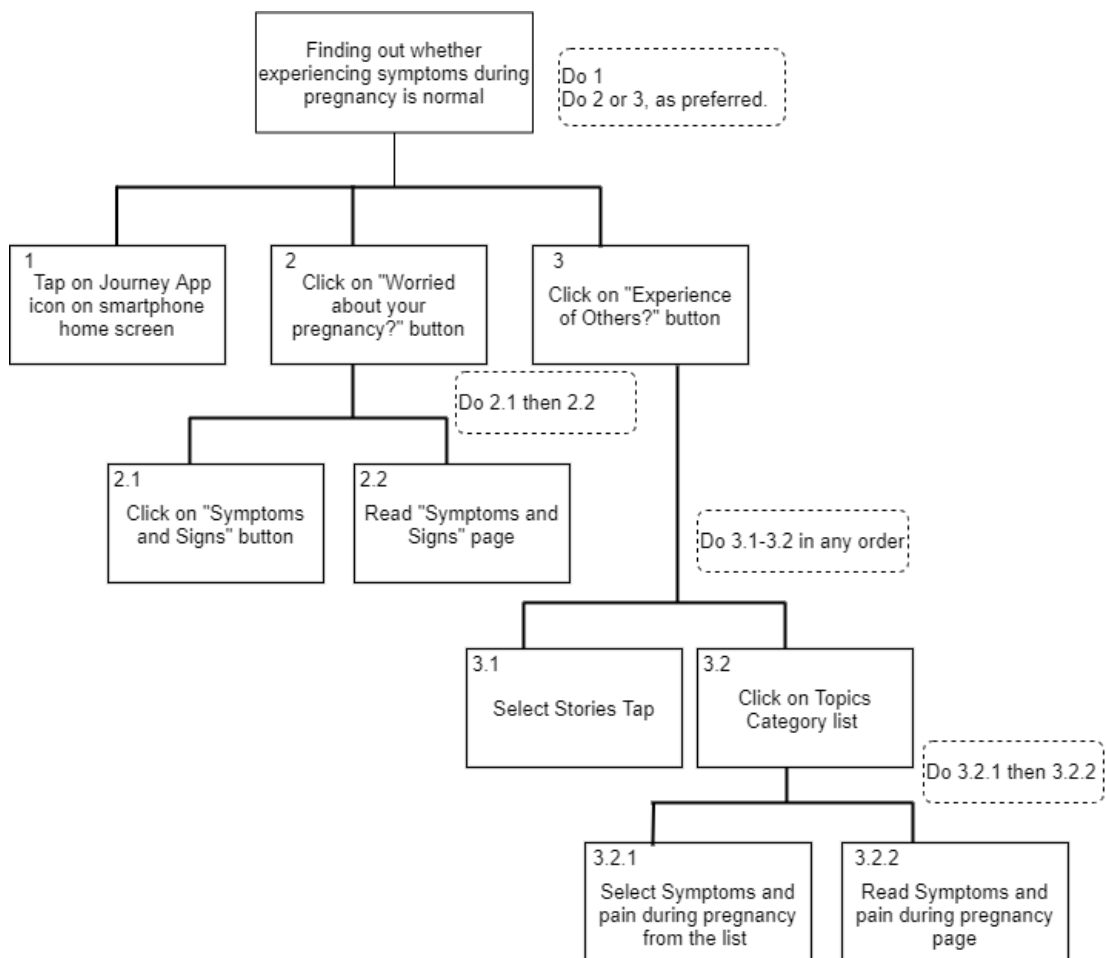


Figure 6.4: Hierarchical task analysis for informational support scenario

of a miscarriage. The hierarchical task analysis for seeking this informational support scenario is shown in Figure 6.4.

6.3.4 Scenario 2: Communication for Network Support

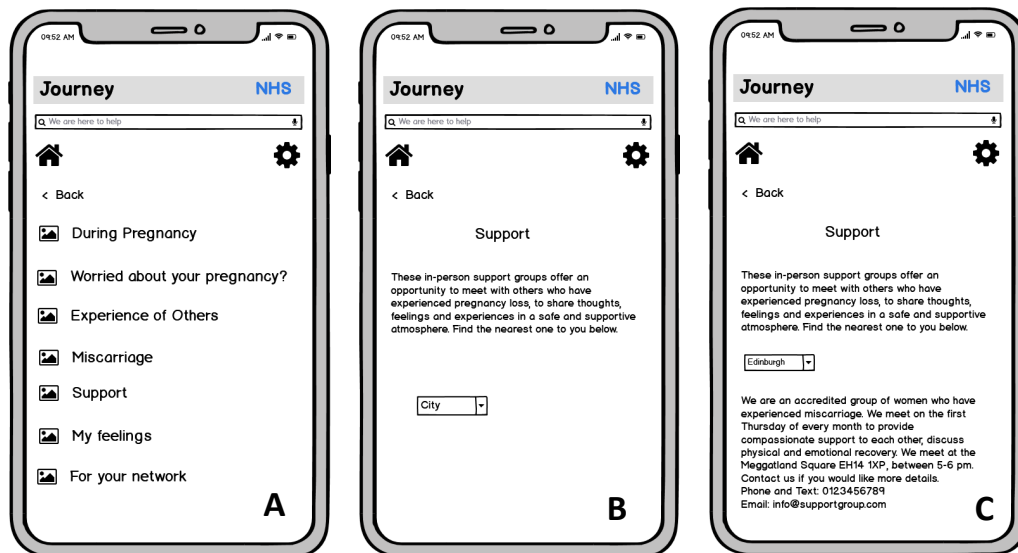


Figure 6.5: Journey app communication for network support scenario

After miscarriage, while Emily was in a period of wanting to escape from what has happened, she doesn't want to engage with people but does want to talk to people who understand what she has been through. While she wasn't sure how to get appropriate support and cope with miscarriage, she remembered the *Journey* app, which helped her find information during her Trigger Events stages, and help her manage her uncertainty in a timely manner. With the benefit of mobility of the smartphone, she quickly taps the *Journey* app icon on her smartphone's home screen (DG1). She clicks on the "Support" button in the app (c.f. Figure 6.5A), estimating that from there she would know how to get help and where to go for support. Tapping on "Support" brings her to another page, where she selects "Edinburgh" from the "City" drop-down list in order to find support services in her local area that she can reach out to (c.f. Figure 6.5B). Selecting "Edinburgh" from the list brings her to another page displaying a list of authoritative local in-person support groups, which in turn facilitates finding an opportunity for her to meet with other people who have experienced pregnancy loss (DG3, DG4). Those groups are to share thoughts, feelings and experiences in a safe, face-to-face and supportive atmosphere (DG4). She gets reliable details about these groups (DG3),

including the location, day and time of those meetings, as well as phone numbers and emails (DG6) (c.f. Figure 6.5C).

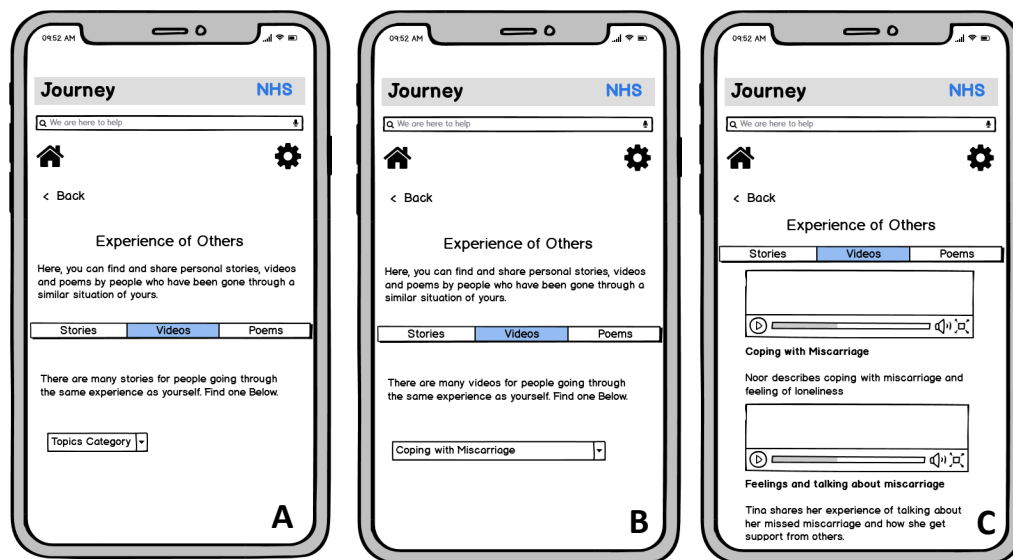


Figure 6.6: Journey app communication for network support scenario

Alternatively, being familiar with the app (DG1), she might like to read about other women who have experienced miscarriage and how they coped with their pregnancy loss. From the "Experience of Other" button on the main page, which combines different experiences of people who have been through similar situations, Emily can choose either to read text of other people's stories coping with miscarriage, and how they handled their grief, or watch a video instead, as preferred (DG6). This drop-down list facilitates Emily to find topics of other people's experiences related to their coping tips, grieving ways and much more (DG4) (c.f. Figure 6.6A). She selects to watch a video this time, and can select from the drop-down list topics related to coping tips (c.f. Figure 6.6B). This takes her to another page, which presents videos of other people who experienced miscarriage, and who have shared their experiences anonymously with the community about how they cope (c.f. Figure 6.6C). Through using the *Journey* app, Emily was able to link up with trustworthy compassionate services to discuss physical and emotional recovery, and to read other women's stories before disclosing her own while she was in a raw emotional state. The hierarchical task analysis for seeking this network support scenario is shown in Figure 6.7.

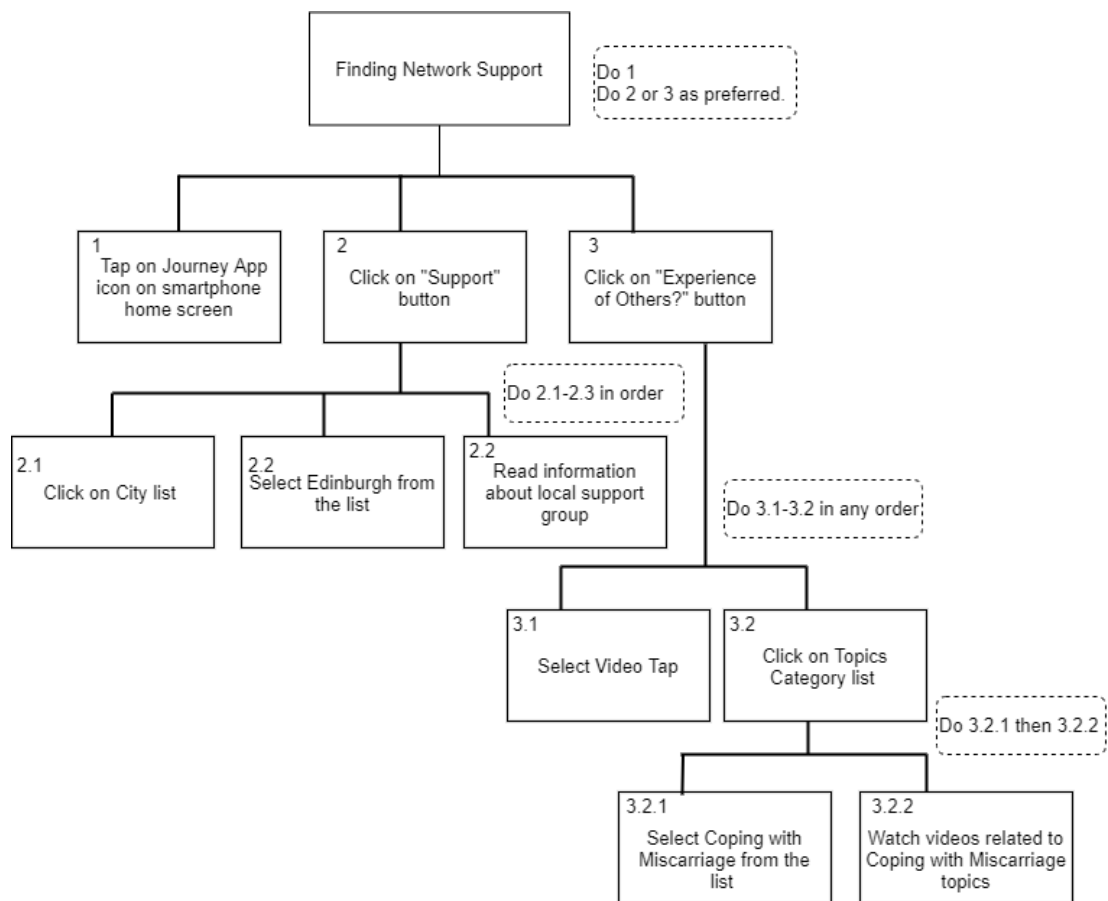


Figure 6.7: Hierarchical task analysis for network support scenario

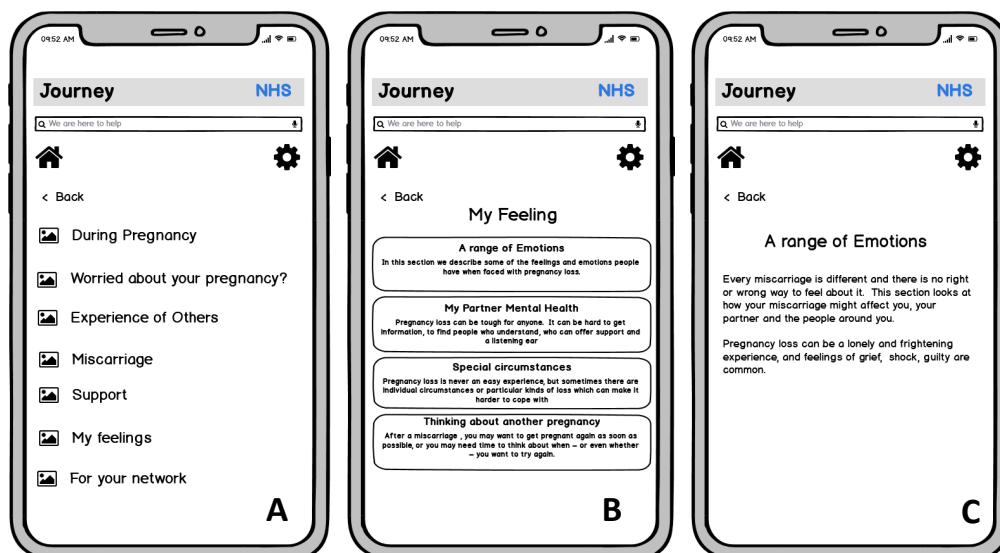


Figure 6.8: Journey app communication for emotional support scenario

6.3.5 Scenario 3: Communication for Emotional Support

Sophei became pregnant again after she experienced her first miscarriage. She attended her second ultrasound scan appointment with her partner at the hospital. Unfortunately, during this visit she learned that there was no heartbeat and a miscarriage was confirmed. Sophei and her partner were invited into the consultancy room where a midwife then explained the options and what would happen next. After discussing the options with the midwife, Sophei decided on the option of taking a pill and returning home. The midwife shared information on what Sophei could expect on the physical aspects of miscarriage, and pointed her to the *Journey* app, to find trusted information, support services and resources about what to expect next (DG2, DG3, DG4).

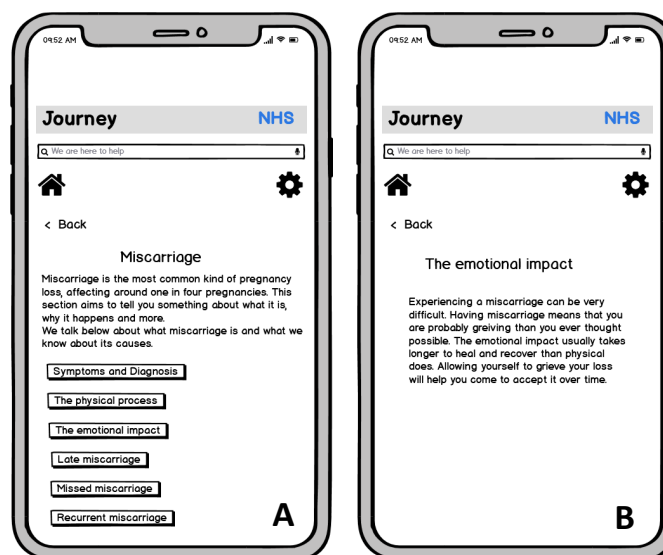


Figure 6.9: Journey app communication for emotional support scenario

However, she did not get as much information as she would have liked about the emotional impact. She remembered the *Journey* app, which she had previously used for the purpose of finding local support groups during her first miscarriage. So, she opens the app and selects the "My Feelings" button (c.f. Figure 6.8A). She is faced with a collection of reliable information about the emotional effects (DG3) (c.f. Figure 6.8B). The in-person support group, which she joined after her first miscarriage, did help (DG4), but additionally, the app helps her to find more reliable advice on how to cope with the psychological impact of experiencing miscarriage (DG3) (c.f. Figure 6.8C).

Alternatively, she might select the "Miscarriage" button on the main page. This takes

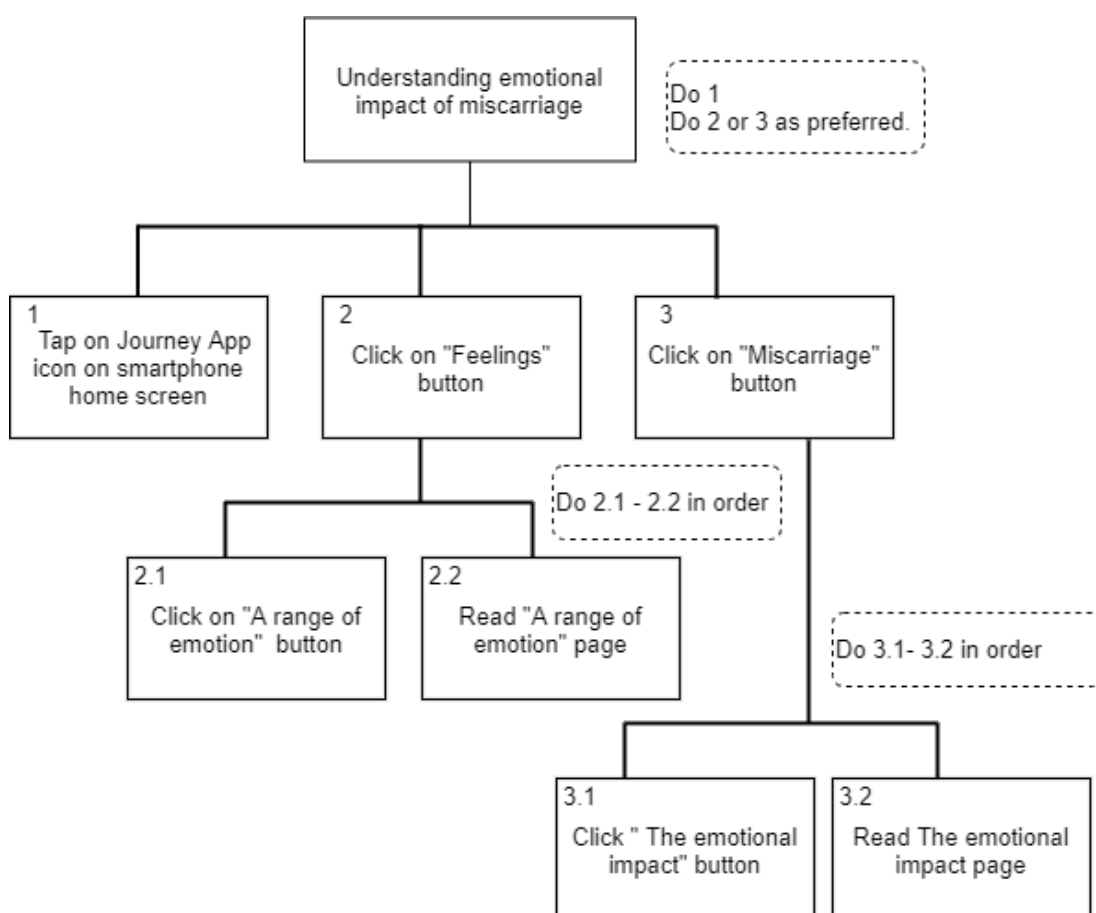


Figure 6.10: Hierarchical task analysis for emotional support scenario

her to another page, which presents a collection of reliable guidance and advice including the emotional effects of miscarriage (c.f. Figure 6.9A). From this page, she choose to read about the emotional impact of miscarriage (c.f. Figure 6.9B). Using the *Journey* app helps her to understand her feelings and thinking patterns, and challenge the thoughts contributing negatively to her wellbeing to help develop a more balanced perspective towards what has happened. The hierarchical task analysis for seeking this emotional support scenario is shown in Figure 6.10.

6.3.6 Scenario 4: Communication for Esteem Support

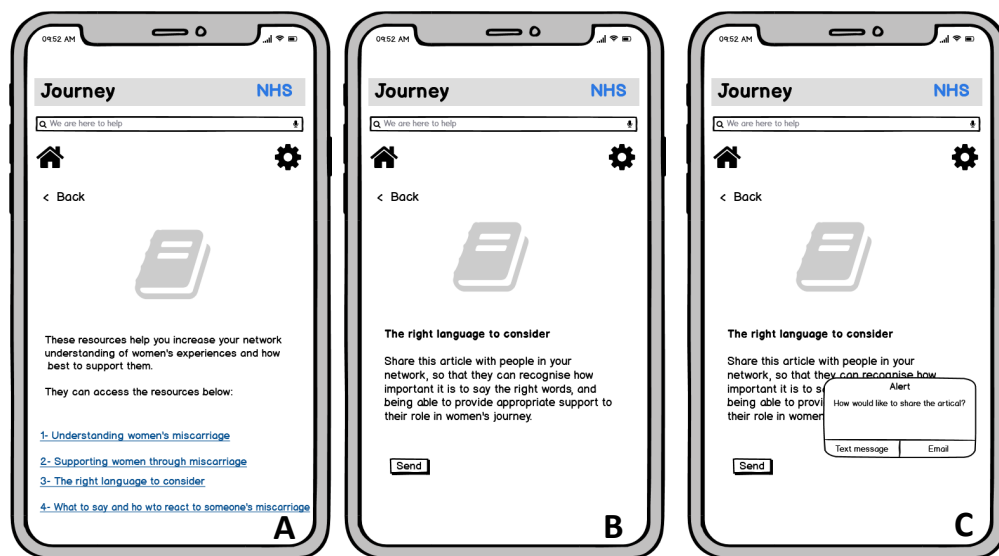


Figure 6.11: Journey app communication for esteem support scenario

After some time, Sophei felt that there needed to be a shift in society and more openness was needed to discuss miscarriage, but that people needed to learn the right language when talking about this sensitive subject. So, she opens the app and selects the "For your network" button (DG5) (c.f. Figure 6.11A). She is faced with a collection of articles that she could share with people in her Circle of Care to increase their understanding of her miscarriage experiences and how best to support her and her partner (DG5). She clicks "The right language to consider" article (DG3, DG6). This shows her the article so she can read it and make sure it is the right one to share with her network to provide insights on how to use the right language and explain that she felt that she and her husband lost a member of the family and people should better understand the language needed in these circumstances when people feel bereaved (c.f. Figure

6.11B).

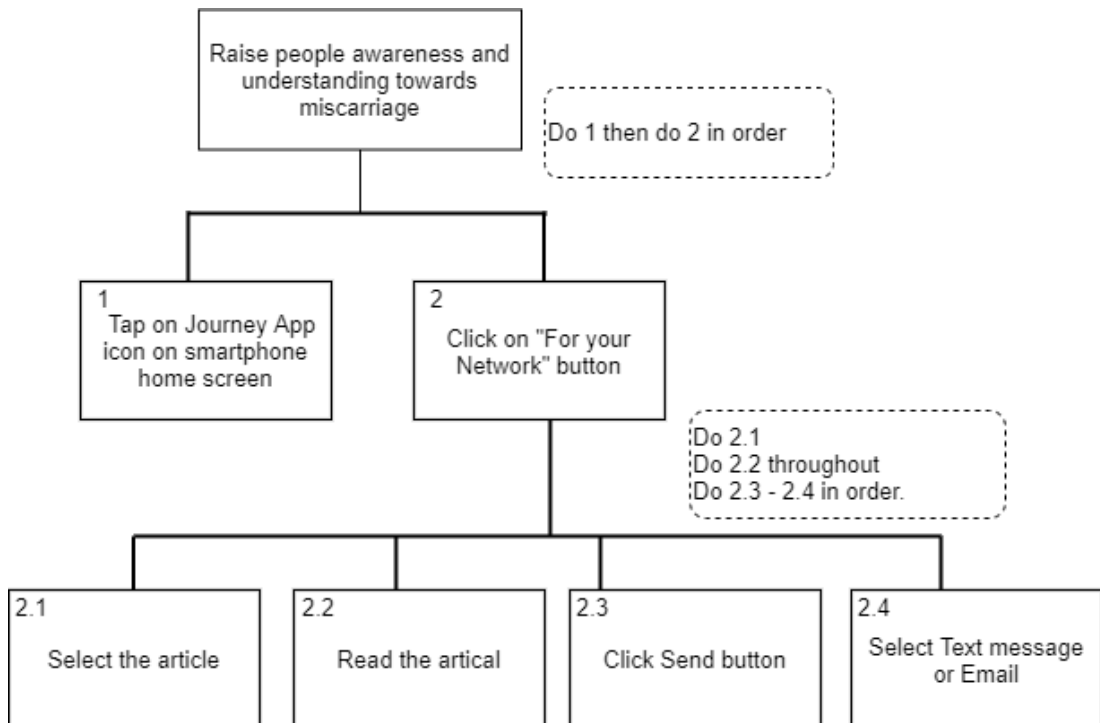


Figure 6.12: Hierarchical task analysis for esteem support scenario

She then clicks the "Send" button on the left side, and sees a pop-up requesting to choose on how she prefers to send the article, via "text" or "email" (DG6) (c.f. Figure 6.11C). Through using the app, Sophei was able to notify her entire network about her needs and increase her network's understanding of womens' miscarriage experiences, to navigate their own discomfort by sharing resources on how best to support women after pregnancy loss, without putting the effort on women for how to educate their care network while her grief is in a raw emotional state (DG5). The hierarchical task analysis for seeking this esteem support scenario is shown in Figure 6.12.

6.4 Summary

The previous studies described in Chapter 3 and Chapter 4 reiterate the effectiveness of social support provision as a crucial element for improving womens' wellbeing and the miscarriage experience. Subsequently, these findings reinforced the significance of continuous social support for helping women to cope, along with revealing the various opportunities to provide and use STS either within or post-miscarriage. Even following miscarriage, social support proved to be challenging to gain as the situation remained

critical due to the stigma surrounding miscarriage. The initial investigation of the role of the MCCM revealed the importance of technology in order to provide the needed social support. Moreover, as we saw in Chapter 4, we realised the need to further investigate the role of technology to provide continuous healthcare social support provisions, in addition to facilitating easy access to network support, and educating people in society to have good awareness about miscarriage.

This chapter described the design of mobile application technology to support women with miscarriage experience. First, the chapter explored the design goals for a digital solution to deliver the needed support. Then, the *Journey* app was designed as a smart-phone technology to support women who have miscarried. The designed scenario in this chapter impels us to integrate the consideration of STS requirements with consideration of how a system might impact upon the women who are experiencing or have experienced miscarriage' action and experiences in term of accessing the functionality of the system and what the user will experience in doing so. However, we still need to review and investigate how those design goals might impact the women seeking social support practices. Therefore, the next chapter describes the evaluation of the prototype of *Journey* app with women who have experienced miscarriage and reports on how mobile application tools can be used for continuous care and can facilitate social support.

*“Perfection is no one’s attribute.
It is an honour to have limited
defects. “*

Bashār ibn Burd

7

Facilitating Social Support Among Miscarriage Circle of Care

7.1 Introduction

In this chapter, we describe another series of co-design workshops that were conducted in order to evaluate the design goals generated for a socio-technical system (STS) (an app called *Journey*, c.f. Chapter 6), which was designed in response to the exploratory ARC study described in Chapter 3, the initial series of co-design workshops described in Chapter 4, and the online card sorting study described in Chapter 5.

This second series of co-design workshops aimed to run a formative evaluation of the design of the *Journey* prototype mobile application, and to explore the design options further. This would lead to hopefully establishing agreement on the key design concepts for the STS that would be the basis for the preliminary design. The chapter then ends with design considerations and opportunities for digital technologies to support a healthcare-integrated mobile application.

Specifically, this chapter aim to answer the third research question listed in Chapter 1, Section 1.1). The third research question is:

[RQ3] How might we facilitate social support among women who experience miscarriage and their care network?

- What form of intervention might help the experience of women who have miscarried and could this support be provided through a socio-technical system?
- How do we design a socio-technical system which supports women in a sensitive manner?

7.2 Methods

In this chapter, we focused on evaluating the prototype, introduce the new context of use, identify the need for new design requirements or system features, and determine the participants' satisfaction and acceptance of the mobile application and its features for the purpose of supporting women who are experiencing or have experienced miscarriage. Design review and formative evaluation are reflective activities, and they can identify and integrate different perspectives, and help designers to raise concrete and detailed design issues to guide further work [Carrol, 1999, Nieveen and Folmer, 2013]. Therefore, we used formative evaluation method to engaged women who have experienced miscarriage in the workshop individually to offer a comfortable and private environment for the participant to express their view on the prototype, and realise their personal expertise and have a sense of ownership to drive the evaluation discussions.

7.2.1 Recruitment

Below is the inclusion criteria for recruitment:

1. women who have experienced at least one miscarriage, and
2. who are comfortable taking part in a study that is conducted in English and/or Arabic.

We recruited women through:

1. posting into two Facebook groups that have been created and conducted for the purpose of the previous study [Alqassim et al., 2019], and

2. posting into a Facebook group for our charity and support group partner (i.e., the Miscarriage Association), and
3. the thesis author and supervisor disseminating information about the study through their personal and social media network, and
4. distributing leaflets in libraries and charity shops in central Edinburgh city.

7.2.2 Participants

This workshops sample consisted of 5 women who have experienced at least one miscarriage. All of them have experienced miscarriage care in the UK healthcare system. Two of the participants were from the original set of the first series of the workshop reported in Chapter 4, Section 4.2.2.

7.2.3 Study Design

To evaluate the prototype, we used a mixed of qualitative and quantitative data collection methods with the aim of using a triangulated method to solicit responses from participants about the prototype evaluation. The workshops were structured based on the four main activities to evaluate a low fidelity prototype, as described below:

7.2.3.1 Activity 1: Task Completions

Users are behaving and interacting with a technology, these behaviors form the cornerstone of performance metrics. In order to measure how users might behave or interact with *Journey* app, we measure the percentage of tasks successfully completed by participants and errors occurred.

To measure task success, each task that users are asked to perform must have a clear end state or goal. Therefore, we first defined what constitutes success, and define success criteria for each task to avoid running the risk of constructing a poorly worded task and not collecting clean success data. As a results, each participant was asked to perform five tasks which were chosen as being representative and covered the full range of features offered by the prototype mobile application. These tasks were inspired from the scenarios presented in Chapter 6. These include: (1) finding out for certain symptoms if it falls into a normal range, (2) reading about other women who have had the same symptoms, and different outcomes (miscarriage / pregnancy), (3) find a local

support group, (4) finding information to help understand a range of complex emotion, and (5) send information about miscarriage to family member or friend on how to help women cope (c.f. Table 7.1 for the list of the five tasks). We did not disrupt or intervene the thinking process. Help was provided to participants only if they explicitly requested it, and only the essential amount of information to enable them to move on to the next task.

Table 7.1: Tasks which participants carried out for the purpose of measuring task completion in the co-design workshop.

Tasks Numbers	Tasks Usage Scenario
Task 1	Imagine that you are experiencing sudden abdominal pain during the first 12 weeks of pregnancy. How would you use the app to find out whether what you are experiencing is normal?
Task 2	Imagine that you want to know about other women who have had the same symptoms, and different outcomes (miscarriage / pregnancy). How would you use the app to do that?
Task 3	Imagine that the miscarriage has happened, and you would like to find a local support group. How would you use the app to do that?
Task 4	Imagine that you are struggling with your emotions. How would you use the app to find out what is normal in your situation?
Task 5	Imagine that you want to give your family and friends information about miscarriage and how to help you cope. How would you do that using the app

We relied on two types of measuring performance metrics based on [Tullis and Albert, 2013b]. First, we measured task success as it helps show how effectively users are able to complete a given set of tasks. Task success is the most widely used performance metric. Second, we recorded task errors, which reflect the mistakes made during a task as it helps in pointing out particularly misleading or confusing parts of an interface [Tullis and Albert, 2013b].

Although the measurement of task success and errors might be useful for collecting data on how users behaving and interacting with a system, such data does not give full information on overall satisfaction on the part of the user. *User satisfaction* can be an important factor in motivating people to use a system and may affect user performance

[Tullis and Albert, 2013a, Ritter et al., 2014]. Therefore, following measuring the tasks completion, we ask participants to undertake the activities, described next. These activities were used to evaluate the *user satisfaction* and determine the participants' acceptance of the mobile application.

7.2.3.2 Activity 2: Reflective Discussion

We carried out reflective discussion to have the user articulate the answer verbally after completing the task, with the goal of obtaining the participants' immediate interpretation of a given effective task and prototype design and increasing insight to identify the need for new design requirements or system features [Følstad and Hornbæk, 2010]. To avoid results in answers that are difficult to interpret, and to probe the users to make sure they actually completed the task successfully, we asked participants about their overall impression toward the *Journey* app, best and worst aspect of it, what they might change in the app, and how they compare this app to other ways to support miscarriage (c.f. Appendix L for the reflective discussion guide).

In addition, we used personas and seeking social support scenarios to engage the participants in reflective discussion, and to establish a more focused discussion. Personas and scenarios were designed based on (anonymised) womens' miscarriage experiences, as identified in the exploratory ARC study (c.f. Chapter 3) and the first series of co-design workshops (c.f. Chapter 4). several previous studies have found scenarios were useful as focal objects in both design reviews and formative evaluations [Carroll, 1992, Chin Jr et al., 1997, Karat and Bennett, 1991] (c.f. Chapter 6, Section 6.3.2 for more details about the design persona and scenarios).

7.2.3.3 Activity 3: Semi-structured interview

Following the reflective discussion, we carried out semi-structured interviews with each participant. The focus was to further identify the design elements of a STS that responded to the participants' needs, exploring the participants' perceptions of the prototype and the potential of mobile application to provide social support in a timely, safe and convenient manner. We asked participants if they have previously used a similar App for the purpose of miscarriage before, and to gain their opinion for having a feature in the app that could allow access to an online community, to connect with the therapist to discuss their feelings and thoughts, to conduct a live chat with their midwife, and take a photo and send it to her remotely. Additionally, we asked them

if *Journey* app is going to be useful in the future if it exists (c.f. Appendix L for the semi-structured interview guide).

7.2.3.4 Activity 4: Write Love Letter/Breakup Letter

Following this, we asked participants to write Love Letter/Breakup Letter. The Love Letter and the Breakup Letter are two methods that allow participants to express their sentiments about a product or a service through writing a personal letter to a service or product, which usually reveals profound insights about what they expect and value from the service in their lives. Smart Design created The Love Letter/Breakup Letter methods in 2009 [Martin et al., 2012], in which to express thoughts and feelings about a service in an accessible way. The collective insights in the letters inspired the designers at Smart Design for new and evaluating ongoing design projects.

Inspired by Martin et al. [2012], we use Love Letter/Breakup Letter method to allow participants to share stories that are situated in real life experiences about the meaning and place that the *Journey* app would plays in their lives. Moreover, throughout the study conducted in Chapters 3 and 4, we observed that "writing in a dairy" was one of the most coping strategies that participants used following miscarriage. Therefore, we claim that Love Letter/Breakup Letter method might be a suitable technique that allow us to gain deep and revealing understanding about the relationships women who have miscarried might have with *Journey* app in their lives, and what creates moments of connection and delight.

The main aim of administering written Love Letter/Breakup Letter after the test is to observe participants' satisfactions, in order to identify potential problems with the prototype. Information collected usually includes opinions and feelings regarding any difficulties encountered in using the prototype if it exist in the future. A crucial feature of these method lies in the fact that it asks the participants to evaluate the system as a whole, rather than specific aspects [Martin et al., 2012]. In order to evaluate and gain insights into why the *Journey* app would be useful and compete for the attention of women who are experiencing or have experienced miscarriage, the Love Letter gets at the heart of what they feel during their experiences when interacting with the prototype. On the other hand, the Breakup Letter was used to understand how, when and where a relationship with this prototype will turn sour, in order to evaluate and better understand what would make the participants abandon using the *Journey* app to communicate their social support needs.

We gave the participants pens and paper. Each participant had 10 minutes to write their letters, and we asked them to write a response for the following questions:

Love Letter: Could you please write a personal message to this app and tell me how you met and why you chose to use it?”

Breakup Letter: Could you please write a personal message to this app and tell me how you met why you want to break up with it? What other apps have you been seeing? Where has your heart taken you now?”

7.2.4 Procedure

Once the participant indicated an initial interest in the study, she received a participant information sheet via email. Each participant was asked to review the sheet for as long as they liked and enquire about any concerns they had. Once she was happy to proceed, we agreed on the date and time to run the co-design workshop. Upon the agreed date of the workshop, we anticipated that the participant had read the participant information sheet before the workshop. If not, we asked her whether she preferred us to talk her through it or whether she would like to read it herself before we began. Once the participant signed the consent form and agreed to participate, we carried out the one-to-one co-design workshop. Both sets of participant information sheet and consent form can be seen in the Appendix B.

In each workshop session, we began by welcoming the participants, they were told that they were to take part in a formative evaluation study and were to work with a prototype of a mobile application. An interactive version of the prototype was made available for participant reviews on a provided laptop. Prior to actual evaluation, the study began with a short explanation on the testing the prototype, with the aim of enabling participants to gain a general understanding of the standard prototype system design and its navigational characteristic. Subsequently, participants carried out **activity 1: task completion** and completed the series of five tasks that we mentioned above in Table 7.1.

We then carried out **activity 2: reflective discussion** with a set of follow-up questions of **activity 3: semi-structured interview**. The participants were encouraged to discuss the situations where they encountered problems or expressed concerns and then discuss the possible causes of the situation or possible design changes that could be implemented to address the identified issues.

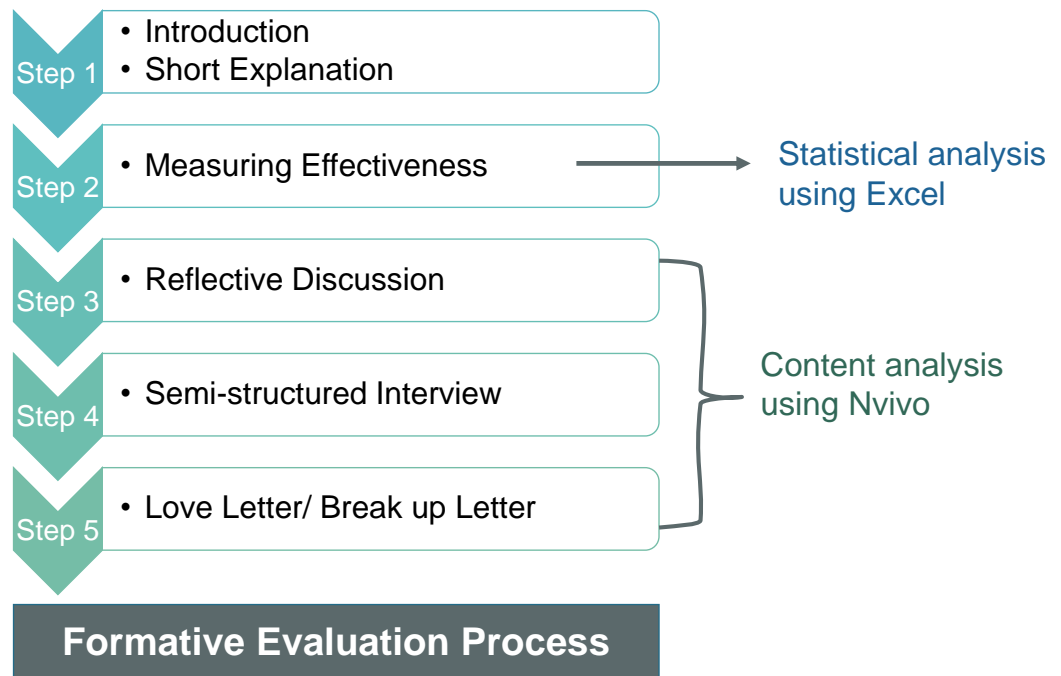


Figure 7.1: Formative evaluation process carried out during the workshop sessions

The workshops concluded by conducting **activity 4: Love Letter/Breakup Letter**, where we asked the participants to write a follow-up letters for the full prototype design and its features, its usefulness, participants' intention to use it, and barriers to the use of this mobile application in the future (c.f. Figure 7.2).

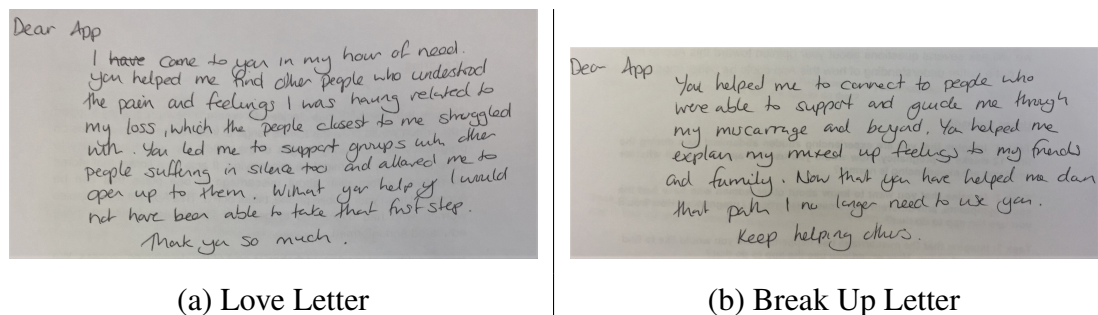


Figure 7.2: Examples of the letters generated by participants for activity 4: love letter and breakup letter methods

Participation in the study lasted approximately one hour and 15 minutes. The workshops took place in a quiet meeting room at the Informatics Forum, University of Edinburgh. The workshop was audio recorded, with photos taken only of the generated letters that the participants wrote after the workshop, (c.f. Figure 7.2). Finally,

participants received a One4all Gift Card equivalent to £20 GBP for their participation in this study.

7.2.5 Data Analysis

Quantitative data generated from measuring task completion activity were analysed using Excel. During the analysis, we quantified and characterised a set of variables related to participants' performance. Specifically, we identified the number of task successes and errors participants made. There are two types of task success: binary success and levels of success. In this study, we used binary success. On the other hand, errors were classified into two main categories: navigation errors occurred when participants did not move as expected, and comprehension errors occurred when participants did not understand the design of the interface [Tullis and Albert, 2013b].

Qualitative data was generated from the reflective discussion activity provided by participants in relation to their user experience, with participants' comments along with semi-structured interviews and love letter/breakup letter activities that were transcribed and analysed using content analysis. In regard to qualitative data, many researchers argued that qualitative data should be analysed immediately after conducting the study [Bryman, 2016, King et al., 2018]. We used this strategy when conducting the co-design workshops in this research which in turn assisted to guide us by indicating where to focus and flagging which issues/areas remained unanswered. Following similar steps of analysis presented under Section 4.2.7, we perform content analysis to interpret the qualitative data. This means that data analysis began with data transcription, familiarisation with the data, coding and producing the analysis. Although these steps are sequential they did not always happen in isolation of each other – we moved between and within these steps. NVivo software version 11¹ was used to coordinate the coding.

7.3 Findings

In this section, we report our findings of recording the task success and errors and describe the seven sub-themes that resulted from the analysis of the other co-design workshop activities. Generally, the findings reiterate the need for portable and available devices, simple and meaningful labeling, and the provision of social support and

¹<https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>

guidance in a timely, safe and convenient manner. Moreover, we identified clear benefits and challenges of integrating the *Journey* intervention into pregnancy and the healthcare model provision.

7.3.1 Task Completions Measuring

Figure 7.3 shows the success rates for each task. Although the sample size of participants was too small to do reliable tests of significance, it is apparent that the tasks were consistently completed across the participants. As the Figure 7.3, there was not substantial variation between users. Tasks related to learning about other women who have had the same symptoms (Task 2) showed the lowest success rate, followed by finding a local support group (Task 3).

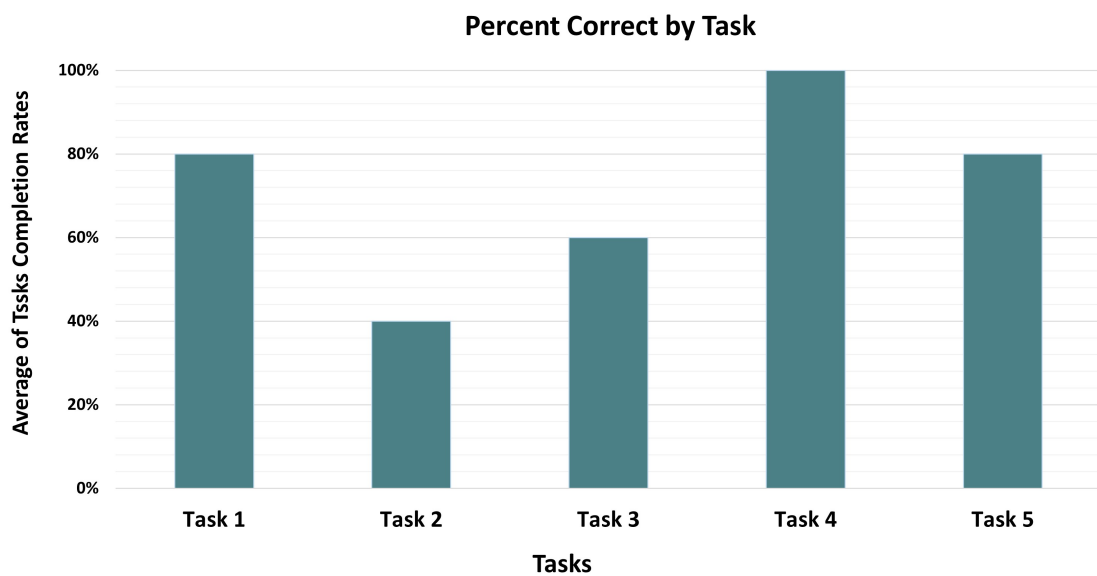


Figure 7.3: Task success rates.

The number of errors participants made while performing tasks and the number of times they requested help are provided in Table 7.2. The absence of errors and request of help in Task 4 is in some sense extremely simple, but on the other hand Tasks 2 and 3 yielded the highest number of errors and requests for help.

The number of errors participants made during testing was higher for Task 2 than Task 3 and consistent with previous observations of the task success rate presented in Figure 7.3. The number of help requests during testing is considered to be higher in Tasks 2 and 3 compared to the rest of the tasks, which Tasks 2 and 3 also have the lowest success rate and resulted in the most errors for participants to complete.

Table 7.2: Types of error by tasks

	Tasks 1	Tasks 2	Tasks 3	Tasks 4	Tasks 5
Request for Help	-	2	1	-	-
Types of Errors					
Navigation	1	4	3	-	1
Comprehension	1	1	1	1	1
Total Errors Numbers	2	5	4	1	2

7.3.2 User Satisfaction

The workshop activities revealed some positive views and limitations and suggestions for improvement for the prototype of the mobile application as presented in Table 7.3. Each of the following quotes identified themes mapped to source events (i.e., Reflective Discussion (RD); semi-structured interview (IV); and Love Letter/Breakup Letter (LLBL)).

Table 7.3: Summary of codes used in analysis. Number of participants refers to participants who made at least one comment during the workshops that was classified as that code. Total instances is the number of comments classified as that code.

Codes Name	Number of participants	Total instances
<i>Positive Views</i>		
Reliable and Trustworthy	5	10
Facilitated Earlier On	5	6
Peer Support Services	4	7
Care Network Sharing knowledge	4	8
<i>Limitations</i>		
Re-structuring the Contents	5	13
Label Changing	3	5
Portal to Healthcare Providers	5	12

7.3.2.1 Positive Views

Reliable and Trustworthy

Having a mobile app that has been introduced to participants by a healthcare provider was ultimately an important feature for participants to decide whether to use the system or not. They shared this perspective when we asked them if they are going to use this app if it exists in the future, as P2 said:

Yes, I will. Particularly this one is provided through the NHS, the most trusted agency for me. When I search about something in google, I usually write what I am looking for and write NHS as a trust point. [P2, IV]²

They feel safe in the knowledge that the app was introduced as a reliable and trustworthy app to use, as P1 expressed when she wrote the love letter:

It was a pleasure to be introduced to you by my healthcare professional. I feel safe in the knowledge that you were introduced as a reliable and trustworthy 'app' to use for knowledge and understanding of my circumstances. [...] I am a person who likes to use technology and find the services you offer a nice convenient and discrete way to get information that I know can be relied on. [P1, LLBL]

Facilitated Earlier On

Participants liked that the app would be available to them in early pregnancy, integrating the functionality to support women who might be miscarrying.

It would be really nice at the beginning where somebody had said to me 'by the way, there is an app', so I got a security blanket that I knew I could look into something. Because when you are in the middle of a crisis and problem you probably will not think about an app. [P1, RD]

This integration might help the women to get easy and timely access to the information and support early on.

Integrating this app into a pregnancy app will be so helpful. While people who find this app after they miscarried, it would be better to have miscarriage app instead earlier on. [P2, IV]

Peer Support Services

Participants felt that the app helped them find other people who understood the pain and feelings they were having related to their loss, which people closest to them struggled with.

²Participants are labeled based on participant number (P#), and the activity data came from (i.e., Reflective Discussion(RD); semi-structured interview(IV); and Love Letter/Breakup Letter(LLBL).

Experience of other, this is really helpful. Because people do not talk about it. You know, people generally do not talk about it, a lot of people do not tell you that they have them. It is really helpful to discuss that you are normal. [P5, RD]

Similarly, P3 expressed the following when we asked her to write a love letter to the prototype:

You led me to the support groups with other people suffering in silence too and allowed me to open up to them. [P3, LLBL]

Moreover, although all participants liked the easy access of information relevant to in-person support groups that are available locally, they expected to see some a variety of support options (i.e., online community) that could adjust according to the womens' support needs during their miscarriage journey.

There should be an option for accessing an online community for people who might struggle meeting people in-person or for those who might go online for the first time, and then will go to in-person groups later on. [P4, IV]

Care Network Sharing knowledge

Most of the participants liked the feature of educating people through the app, which will help people understand and have the knowledge about what to say and how to react to their miscarriage.

I like this idea, and I have not thought about this before. It is good to send something like this to mum saying why are you talking to me like that, here is how you should talk to me. [P1, IV]

I would use to reach out to people during the miscarriage because quite often when had miscarriage, people having no idea what to say to you. It will be quite handy instead of explaining everything to one person and do the same with another person. [P2, RD]

7.3.2.2 Limitations and Suggested Improvements

Separating and Restructuring the Content

Participants suggested that the prototype content should be restructured by giving a miscarriage-specific path, including sub-divider services and information separated from the pregnancy content, expressing that as the worst aspect of the app. Particularly, miscarriage and pregnancy are completely different topics and the support in miscarriage is different than pregnancy, although they are related to each other.

If somebody experienced miscarriage they do not want to go to the pregnancy section, because they just lost a baby. And If I am pregnant I do not want to see miscarriage content. [P4, RD]

If you worried about pregnancy you may not yet experience a miscarriage it might be just shown signs which is not appropriate, because you need to know first that you have a miscarriage before start talking about pregnancy loss. Also trying again is not appropriate to be here, because you just lose one, you just lose your baby so you do not want to read about having another one. [P5, RD]

Similarly, P2 expressed the following when we asked her to write breakup letter to the prototype:

I was also a bit upset by your behaviour I had a miscarriage and ‘ding dong’ there is a lot of stuff about pregnancy hitting me in the face when I look at you. You need to be a bit more sensitive to my feelings. [P2, LLBL]

However, participants still desired to integrate the miscarriage service path in a pregnancy app, expressing that miscarriage is a possibility of their pregnancy and it is good to have it in their head; nevertheless, it needs to be presented in a much more sensitive way. As P1 shared when we were attempting to confirmed whether they desired to have a separate app for miscarriage:

It is okay to have it in there because miscarriage is a possibility of my pregnancy and it is good to have it in my head. For me, it is good to be separate, but they need to be both here. [P1, IV]

This is consistent with the finding of the co-design workshops reported in Section 4.3.1. Participants wanted miscarriage social support to be presented earlier on, they needed reassurance and to feel prepared for the next steps. The clear timeline structure and the social support resources of uncomplicated pregnancies is rapped away once the miscarriage occurs. This is shift many women from a positive pregnancy pathway to what is essentially bereavement. Although there are resources for miscarriage finding and accessing them at the right time is difficult.

However, the findings presented in this chapter are suggesting that the **Journey** app for supporting miscarriage should be designed in a more sensitive way. Ideally, such a system might be integrated into a pregnancy system where experiences and support could be monitored and a seamless transition to miscarriage resources and support could be provided if needed, but without stressing women experiencing healthy pregnancies.

Labelling Changing

Some participants suggested changing the labelling of some buttons in order to simplify and make the purpose of each button clearer to the participants. A list of suggested labelling is presented in the following Table 7.4.

Table 7.4: List of suggested labels by participants

Original Labels	Suggested Labels
Experience of Others	Other Experiencing Miscarriage.
Support	Where you can go for support, Getting Help.
For Your Network	Helping My Network understand, Helping People Understand, Helping Other Understand.

Portal to Healthcare Providers

Participants have liked to see some sort of features that work as a portal to the NHS or healthcare providers, which allows them to contact their formal care network in a timely manner, agreeing that this would be their ideal situation.

I would like to be able to press buttons and phone doctor or email doctor. In some way, I am so triggered that I am important. Having an option like this you should contacting them and telling by the way I am possibly experience miscarriage, that would be my ideal situation. [P1, RD]

When we asked the participants about their impression towards the app enabling them to conduct live chats with midwives and sending photos remotely, participants shared:

That would be good, because sometimes you need to send a picture to your midwife especially for passing some discharge. So, you need to show those things to the health care provider. I am not sure how to do security over it, but it is good to have this. The logo makes me feel that I am talking to NHS midwife whom I will trust to send photo. [P5, IV]

It will be good idea to having an option for talking to one-to-one counselor, but it might be harder to decide to talk with someone, I can see why some people want this. [P3, IV]

7.4 Discussion

The aim of this study was to examine whether the STS approach and the design of the prototype of mobile application could support the miscarriage experience. To do this, we evaluated our empirical prototype with five women, all of them having experienced at least one miscarriage. As a result of the formative evaluation engagement activities, participants found the *Journey* app offered convenient services and a discrete way to get support that they can rely on. They found that the *Journey* app:

1. help them stay informed about their pregnancy, and they will be offered a lot of support to help them navigate their miscarriage path or journey,
2. finding a trustworthy and reliable informational support,
3. easily finding and accessing network support and other people who have experienced miscarriage,
4. proactively educated their care network on how to provide appropriate social support.

However, we identified a set of design issues that could also be used to further improve the prototype of the app design and context. From these issues, we defined a set of general design recommendations that can be used when developing miscarriage social support mobile app with similar design requirements, to support a healthcare-integrated mobile application.

7.4.1 Socio-technical System for Empowering Women

Technologies for connecting the individual with the caregivers often aim to address the limitations of direct support delivery, where the care network plays a central role in providing support [Hong et al., 2012, Yamashita et al., 2013, Chen et al., 2013]. But what about empowering the Miscarriage Circle of Care Model (MCCM) to facilitate social support among the miscarriage circle of care in STS intervention? In designing the *Journey* app, we have identified opportunities for STSs to enable the MCCM and provide social support for women who are experiencing or have experienced miscarriage. Empowering MCCM leads to enhancing womens' knowledge, the knowledge of the formal and informal care network, and thus the knowledge of the whole community and society about miscarriage.

Participants recognise the potential of technology to facilitate social support to be provided in a timely manner. With the design study, in which women had prior experience of miscarriage, the design activities reiterate the need to ease the burden of womens' current practices to navigate loss that is not well recognised by society. These burdens include finding out accurate health provision information, connection to other women who have miscarried, raising the learned knowledge of the community regarding the miscarriage and help society understand stigmatised losses.

7.4.2 Leveraging into Womens' Practice

This research has revealed that women who have miscarried strive to coordinate and communicate their social support needs and concerns by using multiple platforms and online streams using their smartphones. Thus, any designed technology might leverage the existing practices of women who have experienced miscarriage instead of adding burdens to requesting or receiving an appropriate social support.

As an alternative to the most often designed solutions in various contexts of support for patients [Fishbein et al., 2017, Rincon et al., 2017, Mirkovic et al., 2014], we have proposed the use of personal smartphones to access the needed social support, rather than using external devices for accessing social support. Through the use of portable devices that are widely available, we can then build on the existing practice of women who have miscarried to access social support in a timely manner, using a digital solution that is designed to address their needs. Consequently, the women will be able to use these solutions anywhere and at any stage of their miscarriage journey to access their social support needs and communicate with their care networks for support and to share their experiences with others. By building on womens' past experiences with technology, the anticipation is that acceptance and easier adoption will be ensured [Hayes et al., 2007].

7.4.3 Designing Information Architecture with Sensitivity

Evaluating the prototype is evident in the fact that participants, as users, made few errors. However, Tasks 2 and 3 appear to be problematic, although we made an effort to design the menu of the prototype in a way to present the social support depending on where women are in the miscarriage timeline to facilitate the execution of the tasks. Perhaps the essential reason is that these tasks are more complex as a result of the

participants' lack of experience with the layout and navigation of the app. Therefore, participants encountered problems in understanding the organisation of concepts and Information Architecture (IA), which plays an essential role in the way users think about and interact with interfaces in the organisation of information [Lidwell et al., 2010]. From the results, we can conclude that Tasks 2 and 3 appear to be problematic, and it was apparent that the App did not support the full range of participants' requirements. Additionally, the lowest success completion rates and number of errors and requests for help indicate there are possible issues in implementation of the IA of the prototype. This is compatible with our qualitative findings in user satisfaction where women shared their perception towards the *Journey* app for supporting miscarriage concepts and the challenges surrounding integrating the system into a pregnancy system. For example, participants were very unsatisfied with the organisation of the pregnancy and miscarriage content on one screen, and both topics should be separated in the two areas since it provided a better overview of the content.

One of the characteristics of optimal information structure is an IA that fits the user's mental model [Kurniawan and Zaphiris, 2003]. Therefore, to ensure strength and validity that the IA created by the designer matches the users' mental model, there is a need to involve users in various stages of design and development [Bernard, 2000]. According to [Fling, 2009, p. 89] *"The secret is that mobile information architecture isn't all that different from how you might architect software or website; it just has a few added challenges"*. Moreover, IA categories information into a structure which the intended user can understand quickly, locate easily the information for which they are searching [Morville and Rosenfeld, 2006]. In practice, when designing system interfaces, it is fundamental to provide meaningful information organisation to its target users, in order to promote efficient navigation [Shneiderman, 1997]. Hence, the *Journey* app for supporting miscarriage should be designed in a more sensitive way. Since organising IA of a tool often assist people to easily understand, find, manage and exchange information, and therefore making the right decisions [Ding et al., 2017], we acknowledged that IA might benefit from another iteration as the app did not support the full range of participants' requirements. AI categories information into a structure which the intended user can understand quickly, locate easily the information for which they are searching [Morville and Rosenfeld, 2006]. Probably, such an app could be used alongside with pregnancy app and designed in appropriate ways to provide trustworthy informational support in a timely manner, to help easily access other womens'

experiences and stories, proactively educating people in the informal care network, but without stressing women experiencing healthy pregnancies.

7.4.4 Portal to Health Care Providers

The portal to NHS health care provider channel provides a continuum of care to deliver guidance, assurance, and so on. In this respect, we recognise the need to establish portal in the designed solution with the formal care network. These communication channels can facilitate womens' access to guidance, feedback, and reassurance to remain engaged with the miscarriage care. This mean that the formal care network should provide continuity of support throughout the entire miscarriage process.

In these respects, there is a tension between what the women need, and what is currently possible through the healthcare system. Several studies have discussed the complexity of healthcare service context, along with the growing recognition of the importance of building collaboration between the service providers and receivers, alongside the significant role of design to improve the healthcare services based on real experiences [Baxter and Sommerville, 2010, Bowen et al., 2013, Gustavsson et al., 2016, Årsand and Demiris, 2008, Sangiorgi, 2011, Donetto et al., 2015]. In this respect, we therefore found that information governance rules are one of the biggest issues facing the design and adaptability of STS. These policies provide a governance framework for the use of data within the healthcare organisation that sets laws to protect both the rights of patients (e.g., privacy) and the responsibilities of healthcare staff (e.g., procedures employed for confidentiality and patients' data protection).

Therefore, regardless of the value of integrating the *Journey* app into healthcare systems, information governance rules might become one of the biggest issues facing the design and adoptability of STS. Furthermore, even when taking account of the genuine opportunities for STS, we also need to address the many barriers of incorporating STS into the current clinical practices and regulations of the NHS in the UK. Therefore, in order to truly empower women who have experienced miscarriage, it is necessary to involve decision-makers from the NHS in the design process to address the organisational change, review the information governance regulations and policies, and to truly realise the value and need for remote support to improve the miscarriage care service delivery model.

Healthcare policy in the UK emphasises the importance of empowering patients to

make informed decisions [Norton and Furber, 2018]. Integrating the design values and considerations presented in this thesis, which is designed to fit the needs of women who have experienced miscarriage, into a STS will help provide the required type of social support and improve understanding of miscarriage, which, in turn, can impact positively on the wellbeing of women who have miscarried (as discussed in Chapter 3 and 4). Nonetheless, the resulting socio-technical design is complex due to the associated requirements of a cultural and social change in the healthcare infrastructure [Baxter and Sommerville, 2010, Bowen et al., 2013]. The influence of new mechanisms for miscarriage care and data handling techniques can influence information governance and organisational structure positively.

We would conclude that having designed healthcare providers-integrated digital solution to overcome the challenges of the miscarriage healthcare system, the STS structure in healthcare is still required to change to make it work. Previous studies have suggested the need to promote the awareness and increase the engagement of the healthcare decision makers in the change process [Baxter and Sommerville, 2010, Sangiorgi, 2011]. We hence echo the need for adjusting the current healthcare organisational policies in order to create spaces for these changes to be realised with the potential to satisfy the needs of women who have miscarried and improve the miscarriage care model as seen throughout this thesis. Additionally, within the miscarriage care context, women who have miscarried need to be recognised more as a key stakeholder involved in the decision-making within the healthcare services structures. Although current recommendations place the woman at the centre, in practice, implementation is difficult.

In addition, various future directions can be suggested for possible technology design and development based on the design implications highlighted in this research. Thus, future research can investigate the possibilities of organising a group chat with the team of midwives or nurses and techniques to exchange and transfer the womens' information securely between formal care networks. However, one question that remains is whether the midwives or formal care network's workload will allow the delivery of remote support and coordination with the women. Further research would be necessary into the workload of the formal care network and whether this is possibly a resourcing or funding issue on the part of the formal healthcare networks.

7.5 Limitations and Future Work

The work described in this chapter is subject to potential limitations, and the conclusions drawn should be considered in light of these limitations. The limitations centre mainly around the small number of participants. Although the outcome from our study is overall positive, the small sample size limits the generalisability of these results. Additionally, the prototype has been fortunate by being evaluated by women who have miscarried, while it can benefited from involving the multidisciplinary team point of view. For instance, partners and midwives can be involved in the evaluating this prototype, compare and identify common needs and respond to them in the application design.

Whilst these are potential limitations, we also argue that our findings provide an insight into how the support might be provided through STS interventions that might be designed in a sensitive manner. Thus, we believe that, despite the limitations, aside from the design issues observed in the study, participants also identified design features that they found particularly useful such as trustworthy provision, easier access to peer support and helping people understand the circumstance of miscarriage.

There are several ways in which future work could extend or further validate the work done in this chapter. Future work might involve the multidisciplinary team in the design process in order to discover the experiences and challenges of providing and receiving social support within miscarriage circle of care. Future research would thus benefit from expanding the contextual investigation to comprehensively involve decision-makers from the formal care network in the evaluation process to address the organisational change, review the information governance regulations and policies, and to truly realise the value and need for STS support to improve the healthcare service delivery model.

7.6 Summary

In this study, we expanded our contextual exploration reported in Chapter 3, and explored the role of implementing the MCCM in digital solutions in supporting women who have miscarried. Therefore, the design process described in Chapter 4 and Chapter 5 extended the discussion further to integrate a Peer Advisor role into the circle of care as an alternative technique for care network communication and social support

accessing. The findings confirmed the importance of designing digital solutions that promote generalisation and maintain the Peer Advisor's engagement with healthcare model practices.

As a response to the contextual exploration and the womens' support needs in the context of the ARC, and design activities, this chapter evaluated the technology prototype described in Chapter 6. As a result, we discussed the opportunities for a MCCM to facilitate social support for miscarriage (related to RQ3 presented in Chapter 1, Section 1.1). Our exploration, understanding, and design process for STS have revealed a number of opportunities to identify the potential for the sensitive design of digital platforms with the objective of improving the social support services provided to women who are experiencing or have experienced miscarriage. Ultimately, we found that this STS addresses a holistic approach that is loosely coupled with the specific structure of a miscarriage circle of care and is more focused on facilitating womens' social support needs and communication with their care networks. The next chapter combines and discusses the conclusions from all studies and reflects on the research process of STS, as an attempt to answer the research questions of this thesis.

“ I am one of those irritating people, who hang on to the door-knob after they say good-bye, and will neither come back nor go, always remembering something else which must be said... “

Nellie L. McClung in *The Stream Runs Fast*

8

Discussion and Conclusion

8.1 Introduction

In this chapter, we return to the main research questions introduced in Chapter 1, Section 1.1 to summarise the results and discuss these questions in relation to our studies presented throughout this thesis.

The chapter then turns to answering the fourth research question listed in Chapter 1, Section 1.1, *"How can involving women who have miscarried in the research process inform future relevant health care models?"*. While this chapter cannot provide a conclusive description of best practices, it is intended to contribute to the ongoing conversation on these issues. Through reflection on our experiences in conducting research for this thesis, including the difficulties we faced and decisions we made, we derive insights into the role of design, power relations in the community and research in a sensitive area. We conclude with a discussion of limitations, and discuss how the Miscarriage Circle of Care Model (MCCM) developed in this thesis might be implemented within existing miscarriage care in the United States and United Kingdom

healthcare systems.

8.2 Summary of Results and Contribution

As stated in Chapter 1, this thesis makes three main contributions:

1. an in-depth and rich holistic contextual understanding of the social support needs of women who have miscarried, describing in depth their practices and use of technology.
2. extending the Circles of Care Model (CCM) approach to designing socio-technical system (STS) for miscarriage care.
3. proposing empirical design goals for STS for miscarriage care that are grounded in mixed methods research with women from different cultures and different health care systems.

In the following sections, we discuss each contribution in detail. We summarise the answers to the relevant research questions and discuss the degree to which our argument are supported.

8.2.1 Understanding Miscarriage Social Support Needs

The research question in relation to this was:

[RQ1] What are the experiences of women who have miscarried?

c.f. Chapter 3.

- Who are the key people in the care network of women who have miscarried?
- What are the social support needs of women who have experienced miscarriage, and to what extent are these support needs being met?
- To what extent can technology be harnessed to provide additional social support?

We saw evidence in Chapter 2 that there is a gap in understanding the experience of women who have miscarried the social support that they need, and the critical role that the care network play in promoting their wellbeing by providing appropriate social support on this very sensitive and emotional journey (c.f. Section 2.3.2). Moreover, in Chapter 2, we saw evidence that CCM have been successfully used to map health-care organisation and coordination across complex networks that involve continuity of

care [Price, 2010, Price and Lau, 2013] (c.f. Section 2.4.3). Therefore, we propose that shifting towards CCM rather than relying as heavily on specific care network has the potential to improve the quality of support provided.

8.2.1.1 Key People in Womens' Care Network

The ARC study described in Chapter 3 successfully identified the complexity of the formal and informal care networks that are involved in providing social support to women who have miscarried. Due to the large variation between individual participants, we distinguish two groups, the formal and informal care networks (c.f. Figure 3.4). While all kinds of support are valued, the impact of the support depends on a person's role in the care network.

We found that it is important for women to be able to access the desired support from each care network instead of relying as much on a particular one. However, there are barriers to facilitating social support within the care network. We use the CCM to explicitly map the formal and the informal care networks, and their respective roles in providing social support for miscarriage MCCM. Within the MCCM, "Peer Advisor" are central to the provision of holistic care and delivering the social support that women need during and after miscarriage (c.f. Figure 3.10).

8.2.1.2 Womens' Social Support Needs

Regardless of the differences between each miscarriage experience, the ARC study (c.f. Section 3.3.2) highlighted common challenges facing women who have miscarried in receiving appropriate social support needs. We found that all types of social support, informational, nurturant (emotional, esteem and network), and tangible were needed to make participants feel truly supported. Unfortunately, sometimes, participants had to make a significant effort to find sources of social support, and sometimes only found them during a later miscarriage experience. While the informal care network was mostly responsible for providing appropriate tangible support, there was substantial evidence that participants did not receive sufficient informational and nurturant support during and after their miscarriage experience – both from their formal and informal care networks.

8.2.1.3 Technologies for Communication

Participants in this study revealed their need for more social support channels to facilitate communication with their formal and informal care networks. When particular support was needed, which was not being provided by their formal or informal care networks, participants searched for sources of support online. Our study shows that online social support sources sought by participants were varied, although focused on a few online streams. There was no single forum, app or platform that was unequivocally endorsed by all women using it – not even the platform that all women in the ARC study had in common, Facebook. Additionally, all participants showed their preference for using smartphones on a daily basis. Thus, we realised the importance of designing a social support communication platform that would scaffold the MCCM.

8.2.1.4 Summary of Contribution

Our results support our argument, but there are limitations to this (discussed in Section 3.5) mainly centred about the sample of the participants. The participants in this study were predominantly white, well educated, and established Facebook users which might reflect their use of technology and online platforms as a resource to provide support. Therefore, the results need to be considered under these limitations, and any future work may want to consider the suggested improvements in Section 3.5 such as to reach people from lower socioeconomic strata, and people from non-white populations.

Despite the limitations, as pointed out in Section 3.5, the findings are not that dissimilar to what might be expected from observational studies on the experience of women who have miscarriage in terms of the lack of social support that they received, suggesting the CCM approach is viable, and therefore our argument supported. There is value in the findings which contribute to the knowledge by *providing an in-depth and rich holistic contextual understanding of the social support needs of women who have miscarried, describing in depth their practices and use of technology.*

8.2.2 Designing for Miscarriage Circle of Care

The research question in relation to this was:

[RQ2] How might we support the experience of women with miscarriage through design?

c.f. Chapters 4, 5, and 6.

- How do women who have miscarried communicate with their care network?
- How can we leverage technology to increase social support and make existing social support easier to access?
- How technology should be designs to be aligned to the Circle of Care Model?

We saw evidence in Chapter 2 for previous attempts of technology for supporting miscarriage have emerged from clinical perspectives [Kersting et al., 2011] or have focused on self-disclosure tools designed for women to access support [Andalibi and Forte, 2018]. Regardless of the positive outcomes of these technological interventions, by necessity, focus on particular aspects of support provision. We argue the role of technology in providing social support for women who have miscarried from a more holistic perspective that integrates formal and informal care networks. Additionally, the ARC exploratory study in Chapter 3 showed the preference of women who have miscarried for using smartphones when communicating with their care networks or seeking social support. We argued for a possible smartphone application as a technology solution intended to linking women who have miscarried to their circle of care, and enabling their care networks to carry out their roles in the MCCM.

8.2.2.1 Womens' Communication with their Care Network

Our findings presented a detailed understanding of the nature of communication with women who have miscarried and their care networks, and reiterated a clear need for technology that links women to people in the miscarriage circle of care, which helps them meet their varied social support needs. Our findings provided many examples of how women who have miscarried communicate with their care network through various means. Some of these examples were person to person (e.g., talking to the therapist), others were one way connection (e.g., searching for others' stories). Some are synchronous (e.g., a phone call to a midwife) and some asynchronous (e.g., text family). These communication practices demonstrated the various dimensions of the social support needs of the women who have miscarried.

8.2.2.2 Leveraging Technology for Accessing Social Support

In Chapter 4, we identify several clear challenges for a STS designed to facilitate social support; these challenges include the need for clear, upfront informational support to

be presented in early pregnancy, lack of timely response from the trustworthy formal care network provision, the need for network support to be accessible and easily finding other people who have experienced miscarriage, and the need for their care network to become educated in order to provide appropriate social support. Such technology should proactively provide efficient communication that allows seamless access for women to their care networks. This study also help us establish a better understanding of the current use of technology by women who have experienced miscarriage, and to explore participants' views on, and the possibilities for, a mobile application as a solution.

In Chapter 5, we support the design by our attempt to understand the mental model of miscarriage and the information domain that women who have miscarried would like to find in the STS and to their relevant social support. In the online card sorting study, we also obtained data from women who have not experienced miscarriage, which helped capture differences between those who have experienced miscarriage and those who have not, which will be useful in future work on presenting miscarriage related information to members of the circle of care who have not experienced a miscarriage themselves.

8.2.2.3 Designing Technology to aligned to Miscarriage Circle of Care Model

For this question, we set out to investigate design requirements and strategies and STS to promote the MCCM adoption in the existing practice of women who have experienced miscarriage, and augment their communicating with their formal and informal care networks. We distilled our findings presented in Chapters 3, 4, and 5 into actionable design goals, which were then instantiated in a wireframe prototype of a mobile application. The app was designed with the MCCM in mind, and allows seamless access to social support, and the people who could help during and after miscarriages and when needed.

8.2.2.4 Summary of Contribution

Whilst our results show support for our arguments, we must consider the limitations of the studies about sample size and small number of methods used in co-design workshops (c.f. Section 4.5), and lack of representativeness and designing categories of cards that were derived by researchers who had not experienced miscarriage (c.f. Section 5.4).

We describe a number of steps that could be taken in future work, such as considering less digitally connected participants (c.f. Section 4.5) and compare the models of people with miscarriage experience who had different reproductive histories (c.f. Section 5.4) to ensure reliability and generalisation that could provide further validation of the findings.

Despite the limitations, our findings provided insight into the perspective of women who have miscarried on communication with their formal and informal care networks with respect to their social support needs. The MCCM provided the boundaries of a useful system for this study, with a comprehensive view of what we observed for the ARC study reported in Chapter 3 in terms of the care networks, communications and social support needs related to women who have experienced miscarriage over their miscarriage journey. Our findings contribute by *extending the CCM approach to designing a STS for miscarriage care*.

8.2.3 Facilitating Social Support Among Miscarriage Circle of Care

The research question in relation to this was:

[RQ3] How might we facilitate social support exchanges among women who experience miscarriage and their care network?

c.f. Chapter 7.

- What form of intervention might help the experience of women who have miscarried and could this support be provided through socio-technical systems?
- How do we design a socio-technical system which supports women in a sensitive manner?

We saw evidence in Chapter 2 that there are only a few technology based interventions to support women who have miscarried (c.f. Section 2.4.2). We argue that technology can play a significant part in the provision of social support within a MCCM and enhancing communication between the care networks. Important design requirements include constant accessibility and anonymous disclosure (e.g., internet-based psychotherapy programs [Kersting et al., 2011], and online forums [Betts et al., 2014]). Additionally, based on ARC study findings described in Chapter 3, we argue that women social support needs extended beyond development of an internet-based psy-

chotherapy programme [Kersting et al., 2011], seeking or posting to internet discussion forums [Betts et al., 2014], self-disclosure and discussing on social media sites [Andalibi and Forte, 2018], or embodying the network-level reciprocal disclosure (NLRD) to facilitate exchanging social support at the network level [Andalibi et al., 2018].

8.2.3.1 Socio-technical System for Supporting Miscarriage

For the purposes of this research, we have identified a number of design implications for future socio-technical solutions to meet the particular social support needs of women who have miscarried, from augmenting the current healthcare model and enhancing the communication with their care network, to achieving better social support and sharing knowledge of miscarriage. Our contribution is *Journey*, a wireframe prototype of a mobile application solution, which we designed within the context of the MCCM. We evaluated the prototype in a second round of five 1:1 workshops, which informed the design of a responsive model of support for miscarriage. Our evaluation shows that overall, women considered the prototype to be useful and acceptable, with suggestions for improvements.

8.2.3.2 Designing a Technology to Supports in a Sensitive Manner

We expect that when *Journey* is implemented and evaluated, its main impact will be to improve the communication between women who have miscarried and their formal and informal care networks, to encourage women to reach out for social support, and to enable women to obtain appropriate social support, which was challenging to gain owing to the lack of knowledge and stigma surrounded the topic of miscarriage. Such an app could be used alongside a pregnancy app and designed in appropriate ways to provide trustworthy informational support in a timely manner, to help easily access other women's experiences and stories, proactively educating people in the informal care network, but without stressing women experiencing healthy pregnancies

8.2.3.3 Summary of Contribution

Overall, our results support our arguments, but there are limitations to this (discussed in Section 7.5) mainly centred about the small number of participants who evaluated the *Journey* app which in turn limited the generalisability of the results. We describe a number of steps that could be taken in future work, such as involving decision-makers from the formal care network in the evaluation process to address the organisational

change, review the information governance regulations and policies, and to truly realise the value and need for STS support to improve the healthcare service delivery model (c.f. Section 7.5).

Despite the limitations described in Section 7.5, we have identified the potential for developing an STS that can be integrated by formal healthcare providers to support the women who have miscarried, through providing accurate informational support, easy access to their network support and educating the informal care network to provide appropriate emotional and esteem support. Our findings contribute by *proposing empirical design goals for STSs for miscarriage care that are grounded in mixed methods research with women from different cultures and different health care systems*.

8.3 Insights From the Research Process

In this section, we will draw upon the ARC (c.f. Chapter 3) and co-design workshops (c.f. Chapter 4, and Chapter 7) studies in order to reflect on the role of research, design and power relations in the community for supporting miscarriage. In this regard, four main reflections have been introduced based on our experience of conducting design research with women who have miscarried, involving people who have not experienced miscarriage in the process (c.f. Chapter 5), and consulting with our charity partner from the Miscarriage Association organisation.

The research question in relation to this was:

[RQ4] How can involving women who have miscarried in the research process inform future healthcare models to support Miscarriage?

Previous attempts for supporting miscarriage have emerged from clinical perspectives [Kersting et al., 2011] or have focused on self-disclosure tools designed for women to access support [Andalibi and Forte, 2018]. Regardless of the positive outcomes of these technological interventions, we still need further understanding of the opportunities and methods to co-design with the women who have miscarried in a social support context. Given the importance of the role of women who have miscarried in the MCCM, we would hence argue the need to engage those women who have miscarried equally as designer in the design process, so creating balanced perspectives in the design of technical solutions.

The design-centred methodology presented in this research has sought to facilitate the contextual exploration, definition of user requirements, and introduction a prototype for a STS in response to an evolved understanding of miscarriage social support needs. To this end, particular attention has been given to the central role the participants (i.e., women who have experienced miscarriage) played in the design process and how the design and the relevant co-design activities should respond to their practices and experiences.

8.3.1 Creating Balanced Perspectives

In this research, we have developed the design processes and activities for this complex setting to mitigate the contextual challenges, fulfil the needs of the women who have miscarried and engage them in the design process of technical tools to support their social support needs. Thus, various techniques have been used to engage the participants in the design process, from understanding their miscarriage experience and their mental model to thinking and carefully crafting activities in response to the participants and study context.

We started with ARC contextual inquiries, exploration and observations to discuss personal experiences with social support needs and communications with their care network. After creating these common and safe spaces for reflections, we then scaffolded the design discussions in one-to-one co-design workshop sessions (i.e., women who have miscarried individually as they realise their personal expertise and have a sense of ownership to drive the design discussions). Finally, we examined initial design thoughts using techniques from usability testing (e.g., task analysis, and methods from service design, such as Love Letters/Breakup Letters), as presented in Chapter 7, Section 7.2.3.4), or crafting context-specific scenarios (e.g., Scenario 2: Communication for Network Support - Chapter 6, Section 6.3.4). Through this design process, we were able to expose personal experiences and opinions on STS, as well as to authenticate the results and design outcomes based on the critique of co-design workshop sessions discussed in Chapter 7.

We recommend that the depth of ARC exploration be decided based on the needs and the aim of the design context and research. For example, in Chapter 3, a comprehensive investigation was conducted for miscarriage experience in the name of discovering the challenges facing the women who have miscarried, as a result of the lack of social support and services provided. In Chapter 4 and 7, we focused on exploring and reflecting

the individual experiences with the social support and care network communication, instead of generic investigation. In each phase of the research process, we triangulated data from multiple qualitative and quantitative investigation methods. We found that the process of research through qualitative and quantitative design methods facilitated producing in-depth and analytical insights, so informing our understanding of social support needs, while building a deep and rich narrative of the context of STS, which can then be used to produce original solutions.

Studies in this research were either conducted jointly as group (i.e., women who have experienced miscarriage in one group) as presented in Chapter 3, or separately (i.e., one-to-one co-design workshops sessions for women who have experienced miscarriage in separate sessions), as presented in Chapters 4 and 7. These decisions were based on the aim of the design workshop (i.e., when the focus was only on the design decisions and not critiquing contextual experiences) and the perceived possibilities of creating a balanced collaboration between participants and the thesis author. As a consequence, we were able to note that the joint ARC resulted in innovative discussions observed during this study. Therefore, we have observed the value of group methods with multiple participants to combine and exchange multiple points of view on the design opportunities and decisions between the participants.

Moreover, specific design activities were developed for the co-design workshop sessions in order to establish concrete discussions, provoking innovation and ideation; examples include the personas and scenarios presented in Chapter 6. By placing an emphasis on the exploration and design process, we successfully leveraged a variety of design methods to investigate the individual women's needs and abilities in this context. Since smartphones emerged as a common technological denominator, we designed a prototype of a mobile app (c.f. Chapter 6) as an initial step to examine the practicality of design ideas, explore the participants' design requirements, and surface potential challenges encountered.

Design prototype and scenarios inevitably generate concrete discussions about the required elements of accessing social support. Prototypes were recognised as useful means for exploring and testing design options for digital solutions [Floyd, 1984, Lim et al., 2008, Houde and Hill, 1997]. For the *Journey* app, we designed a low-fidelity prototype to test the broad concepts of communication and healthcare service delivery (c.f. Chapter 6).

8.3.2 Co-learning Opportunities

In working towards more community-based participatory engagement in the design and research process, we, as researchers, provide tools to enable the participants to step into the role of designers. This has been echoed by previous studies [MacLeod et al., 2017a, Vines et al., 2014, Thieme et al., 2013, Almeida et al., 2016, Clarke et al., 2016, Kettley et al., 2015]. Here, the design process helped insofar as it enabled us to express our lack of experience with the context and encourage the women who have miscarried to play the role of experts. As a result, the participants have introduced in-depth insights and contextual explanations based on their experiences with the miscarriage.

Moreover, throughout co-design workshops studies we noticed a high level of participant engagement and enthusiasm towards the configuration of solutions impacting upon their social support needs and the service delivery model. We would suggest that this phenomenon has resulted from working on an issue that was important to the women who took part in this research.

However, involving the women who have miscarried in the research presents several challenges already outlined in our ARC exploration study, as presented in Chapter 3. For instance, women who have miscarried have limited time due to their care-giving responsibilities and/or workload. They may also still be in the coping stage, with limited access to technical solutions for their social support needs. External factors affected some of the womens' engagement with the research (e.g., recalling memories) or with specific methods used (e.g., personal knowledge for design process), For example, some women were crying during the co-design session, and some participants were not able to discuss solutions "out of the box" of NHS regulation. However, this challenge was alleviated in the design workshop as they became more familiar with the design research process, leading us to suggest that the concrete design activities facilitated the innovation process.

The various methods and design activities adopted in the two series of co-design workshops provided a unified language to communicate ideas between women who have miscarried and the thesis author; moreover, they served to promote the participants' collaboration, which led to greater creativity and sped up the design process.

This research aims to synthesise and build upon real experiences of miscarriage to identify design opportunities and co-design STS for and with groups of women who

have experienced miscarriage. Throughout this thesis, we have produced and reconfigured insightful and hopefully useful methods in response to the contextual practices. We hence recommend that this design research be employed to enable participants to engage actively in the process, in order that they be perceived as innovators and can suggest solutions or share their concerns to inform future healthcare models.

8.3.3 Working with and through Emotions

It is worth noting that this research has addressed a challenging and sensitive area of women who have experienced miscarriage. This very emotional experience is not well recognised or talked about in wider society; sometimes, the women have had a child after their last miscarriage, or they have not, or they don't have children at all. Hence, in working with socially and emotionally vulnerable women, some whom were still trying to cope with the reality of miscarriage, the context and nature of this research led to a range of negative and positive emotions that affected the women who have miscarried and the thesis author. During the ARC exploration, which involved conducting focused and secure group study through Facebook online, as reported in Chapter 3, we were able to confirm that most of the women openly shared their miscarriage experiences, emotions and thoughts with us. [Andalibi and Forte \[2018\]](#) found that Facebook was seen as an important social platform, and women who experienced pregnancy loss considered it as a potential disclosure venue.

Moreover, emotional eruptions observed in which some women cried while sharing their miscarriage experiences, and they attempt to share their emotions during these sessions. For example, the women explained that their emotions resulted from being able to meet someone with whom they could talk about the challenges that they experience during and after their miscarriage event. As a consequence, in working within this sensitive area, we experienced sadness, which resulted in experiencing a deep empathetic relationship with the research domain. We have been left with devastating emotional burdens, but these burdens were mitigate with the supervisor during the debrief meeting which conducted to discuss the resulting outcomes.

Hence, the established relationships and conducted methods proved productive and enabled us to understand and design for the heart-felt and sensitive experiences of the participants. However, while we have focused our attention on the research and design process, we have also had a duty of care toward ourselves. In this sense, as researchers, we have had to maintain professional boundaries [\[Wolters et al., 2017\]](#). We consider

the emotional work that we have experienced to be a result of the act of empathising and immersing with the participants and their stories, as often advocated as a crucial element in sensitive areas of HCI engagement [Wolters et al., 2017, Balaam et al., 2019]. Similar strategies have been suggested in other professions, where emotional work is considered as an essential skill instead of a negative experience resulting from working in this area [Wolters et al., 2017, Balaam et al., 2019].

Furthermore, we have realised that working in this sensitive research area requires methods and designing approaches that consider the challenges of the involvement of the participants through the research process and the associated stigma risk. One-to-one co-design workshop sessions were chosen with the women who have miscarried (i.e., instead of group sessions) as the discussions involved sharing women's personal experiences with miscarriage or expressing their opinions about the existing services and social support that they have received or required to be received.

Additionally, the design persona scenarios presented in Chapter 6 were built based on the anonymised and collective practices resulting from the observed experiences of participated women who have experienced miscarriage in the previous design phase. Consequently, we have made significant effort to ensuring that the scenarios could not be related to a particular person in order to avoid creating any emotional barrier to their engagement with the design activity.

We emphasise preparing for and working with emotion is an integral part of research in this sensitive and interdisciplinary domain, which needs to be acknowledged by sensitive awareness and careful planning of the particular context [Wolters et al., 2017, Balaam et al., 2019].

8.3.4 Building Relationships Beyond the Research

Throughout the study, we had a strong working relationship with the UK Miscarriage Association. We acknowledge that these consultations have been beneficial through the research and design process to explore and understand the quality of design of the STS. Establishing relationships with community partners has been increasingly recognised to provide long-term value to society and promote sustainable change [Hayes, 2011, Foth and Axup, 2006, Hayes, 2014].

Throughout this research, we recognised that it is not enough to produce a responsive design, but instead to provide a design that speaks to the perspectives and concerns of

women who have miscarried. Our collaboration partner facilitated access to resources around miscarriage and recruitment of participants through their social media accounts and existing networks. The women who consented to take part in our study were keen to participate; this might be because the current levels of miscarriage intervention are low and frequently related to medical issues rather than communication and social support intervention.

At each stage of the research, women who have experienced miscarriage and the Miscarriage Association charity were involved in the design of the study, and their views were taken into consideration. In addition, because we have learned that this research was of value and importance to participants as well as to us, we decided to build public websites to share the results with those who have been affected by miscarriage and the general public¹. The findings of some studies in this thesis have been disseminated to participants and the Miscarriage Association for the purpose of the CBPR process and we will share the dissertation and associated publication with participants who request it in future. Sharing findings in an accessible format will allow us to contribute back to the participants and population we worked with.

As a result of CBPR, a strong relationship was built between the thesis author and the Miscarriage Association charity. The thesis author was invited to attend a Scottish Parliament Debate on miscarriage on 10 December 2019 [Scottish National Party, 2019], where the thesis author met with other people who all shared the same perception towards changing society and raising the awareness of miscarriage, as well as enabling technology to help with this. Briefly, the Scottish Parliament Debate focused on easing the burden and the pain of miscarriage, how the couple has to discover the resources and information on support services themselves. Miscarriage is a real issue in Scotland, and the debate mentioned how Government, NHS and society can take an action to improve it. For example, by providing the women and their families with easily accessible information and support would be a huge step forward [Scottish National Party, 2019].

Our prolonged engagement with the participants and charity partners has helped to establish affinity and trust with them. It has also served to manage the power relations between women who have miscarried and the researcher while coordinating their efforts. We made sure to engage women and researchers equally in the design process, allowing the women to express themselves in a multitude of ways to provide design so-

¹<https://blogs.ed.ac.uk/mona-alcassim/>

lutions that combine their social support needs. Furthermore, the process enabled the women who have miscarried to transition from being less experienced design partners to becoming more active researchers while recognising their own expertise and critical role in improving the importance of social support needs and awareness for society.

8.4 Limitations

Participants of this research were more likely to be comfortable talking about their experience and this may tend to make them feel more empowered about their miscarriage experience. It is possible that their experiences may be different from those of women who are less comfortable with talking experience of miscarriage. Additionally, women who did not have access or were less engaged in using technology may also have a different perspective, since they would seek support elsewhere, which might lead to the further exclusion of women who are already disadvantaged by the digital divide.

Because this thesis focuses on socio-technical interventions, we chose to study women who are likely to be early adopters; they are already willing to be helped through technology. Future work might build on this foundation by considering less digitally connected participants.

Moreover, there was considerable variation in participants' reproductive histories. For example, some participants had a history of recurrent miscarriages, which might require different clinical management. Others had undergone fertility treatment, which suggests that the MCCM may need to be expanded to interface with fertility care.

In addition, the stories the participants shared took place over several decades, with some being very recent. Care provision has changed during this time, although as some of the most recent experiences document, there is still considerable room for improvement in miscarriage care. We acknowledge that health services are fully aware of the need for better social support, and are taking steps to provide this [Engel and Rempel, 2015, Shorter et al., 2019].

Furthermore, in this thesis we have included participants with a wide range of miscarriage experiences. We have deliberately recruited diversely, but have not explicitly sought to cover a variety of faiths and socioeconomic backgrounds. For example, Muslim women's spiritual needs might benefit from bringing attention to this in designing a solution that addresses those particular needs in this specific design space.

Moreover, we did not recruit any participants who had experienced miscarriage, but who did not identify as female. We acknowledge that these people will have additional challenges when navigating the miscarriage experience. Rather, we respect that participants' experiences with their own miscarriage are individual and influenced by their own environment and past experiences.

Although the research design is a prototype of technology for social support exchange within a miscarriage circle of care, the design field faces some limitations. The prototype was designed with only women who have miscarried, and only one study of this research involved women who have not. This approach has made it difficult to argue the generalisability of the findings, being that we cannot predict the effects of the integration of the digital solution into real clinical practices and how they could impact formal care network workload. We expect that several additional cycles of co-design will be required in order to arrive at a tool that is ready for deployment in practice.

Our study also focused on the women experiencing miscarriage, not on the experience of the people in their formal and informal care networks (e.g., partner), who often also need support [Engel and Rempel, 2015, Farren et al., 2018]. Although we have engaged people who have not experienced miscarriage in one part of this research (c.f. Chapter 5, future studies should involve more people from the informal and formal care networks, and people who have miscarried with various miscarriage complications and reproductive histories.

Future research would thus benefit from expanding the contextual investigation to comprehensively involve the multidisciplinary team in the design process in order to discover the experiences and challenges of providing and receiving social support within miscarriage circle of care, from the multidisciplinary team point of view. For instance, partners and midwives can be involved in the design process to investigate, compare and identify common needs and respond to them in the application design.

Similarly, by involving people who have miscarried who have different reproductive histories and concerns, we can identify common issues that affect the STS solution, and investigate where further personalisation is needed.

8.5 Future Directions

8.5.1 Implementing the Journey app in the US and UK Health Care Systems

This research has proposed a variety of relational and technological changes within the miscarriage care service context. However, working to improve the context of healthcare services requires awareness of the regulations and policies imposed by the healthcare organisation in order to understand the operational context.

While implementing the *Journey* app in the healthcare system would be a second major project, we are interested in the initial step towards investigating how this app could be fit in to US and UK healthcare systems.

The ARC study in Chapter 3, which was conducted jointly with Indiana University, engaged participants from the United States and the United Kingdom, two countries with very different healthcare systems. This also ensured variation and allowed us to assess the generalisability of findings across different healthcare systems.

To the best of our knowledge, there are no studies comparing the miscarriage experience between the United States and the United Kingdom; therefore, we limit ourselves to highlighting the main relevant differences between the two healthcare systems. For example, the UK has a single-payer health care system, the National Health Service (NHS), where care is free at the point of delivery. Antenatal care is generally led by midwives and general practitioners (family physicians) [Lewis, 2012]. While many people also have private insurance, most births take place in an NHS hospital. In contrast, the US has an insurance based system with mostly private insurance providers. Antenatal care is generally led by obstetricians and gynaecologists [NIC, 2019, Guideline, 2012]. As a result, a patient's medical care experience and interactions with healthcare providers are significantly different in each location. Nonetheless, some experiences remain very similar.

Although the American Academy of Family Physicians have published guidelines for obstetricians/gynaecologists regarding miscarriage management and treatment of miscarriage [Prine and Macnaughton, 2011], within the context of the US healthcare system it has been acknowledged that the majority of healthcare providers often do not offer women the full range of options [Wallace et al., 2013, Shorter et al., 2019]. Decisions regarding miscarriage management usually occur in the context of complex

emotions, which include disappointment and grief, and women often have diverse preferences; therefore, patient-centered counseling is important to improve patient satisfaction [Boss et al., 2016, Miller et al., 2019]. The MCCM might address this type of gap, allowing for a partnership between providers and patients and providing an ideal opportunity to respect a patient's priorities and concerns. Moreover, women are often unsatisfied with information dissemination, emotional support, timing of management and follow-up or after-care [Shorter et al., 2019]. Since the quality of miscarriage care improves when healthcare providers offer patients medical information and emotional validation, and involve them in clinical decision-making, the *Journey* app might offer these needs throughout the entire miscarriage process and therefore help improve miscarriage care as well as educate the caregivers to integrate these behaviors in such setting.

There are a lot of disparate resources regarding miscarriage care in the US health-care system, but nothing provides centralised information and support throughout the miscarriage process. In the US medical system, early miscarriage is treated more as a medical event than as a loss. However, in the case of late miscarriage (pregnancy losses after the twentieth week of pregnancy), women can be admitted to labor and delivery wards and therefore find access to bereavement support. Just as in the UK, many women will present to the Emergency Department (ED) (UK: Accident and Emergency department A&E) when they see symptoms of miscarriage. As we have seen in Chapter 3, women who present to an ED are often left with a lot of confusion and fear. Women might be able to consult the *Journey* app if they had been recommended it at the beginning of the pregnancy. Moreover, since women who discuss miscarriage concerns while attending follow-up appointments are less likely to suffer from mental health problems than those without this opportunity [Jackman et al., 1991], the *Journey* app might enhance sensitive after-care services that have the potential to enhance mental health after miscarriage. In addition, the *Journey* app would benefit from presenting relevant information in a way that is easy to assimilate for the ED care team.

On the other hand, more centralised information is provided for miscarriage care in the UK healthcare system [NHS Inform, 2020]. Miscarriage care guidelines are set by the National Institute for Health and Care Excellence (NICE). NICE is an executive institution that publishes guidelines in several areas. These areas include the use of health technologies within the National Health Service (NHS) in the UK, guidance on clinical practice, guidance on health promotion for public sector workers, and guidance

for social care services and users.

Once women experience symptoms during pregnancy, they might be asked to go to the early pregnancy unit. If they experience an early or late miscarriage, they might be asked to go to the maternity ward where they will have some tests and an ultrasound scan [NIC, 2019]. The doctor or midwife will provide options for the treatment, and it is totally the decision of the women on how they would like to proceed. Theoretically, access to bereavement support is offered at this point; however, practically, as the ARC findings show, this is not always the case. Norton and Furber [2018] ran in-depth semi-structured interviews with 10 participants recruited from early pregnancy assessment unit (EPAU) to explore the experiences of women who have experienced miscarriage in the UK. They found that the negative experiences were related to waiting for an appointment, which is difficult to endure and is associated with increased levels of anxiety, stress and uncertainty about the viability of their pregnancy. Moreover, inadequate communication occurred between women and the EPAU staff. In this context, a solution like the one envisaged in our *Journey* app might play a central role in enhancing the provision of care for women who are experiencing or have experienced miscarriage. In addition, the current organisation of miscarriage care does not accommodate follow-up support after miscarriage [NIC, 2019]. As we have noted throughout this research, women need more support in coping strategies with different situations. We have proposed instead that a healthcare provider-integrated STS solution might be used to address this challenge by facilitating social support exchanges that can include after care.

Both the UK and the US systems have room for improvement to ensure women receive the social support and physical and emotional care they need. Indeed, there is a need for enhancing patient-centred care in both systems. For sustainable and dependable change, adjustment to the organisational systems might be required to implement the technological solution in the organisational context. As a result, we have come to recognise that the prototype will benefit greatly from another iteration to engage the organisational decision-makers in the design process in order to unify and permit changes that identify the opportunity to integrate this STS into a pregnancy app provided by NHS and from a healthcare provider perspective. This is future work that needs to be carried out before the prototype is implemented, because healthcare systems requirements will place strong constraints on data management, and interoperability with existing health care systems is not trivial.

The amount of time and resources given to support miscarriage and women who have suffered from it is a policy decision on the part of the health service provider [Norton and Furber, 2018]. Hence, it is not principles that prevent women who have miscarried from having continuous support, but a resource issue. For example, the current policy offers limited contact with healthcare providers, suggesting that approaches to augment this support or optimise interaction are highly desirable (e.g., through STSs).

Sustainable and genuine adoption of technology is crucial to evaluate its real impact. This also provides opportunities to extend the research to investigate the relevant organisational changes [Hayes, 2011]. Further studies can then focus on evaluating and reiterating the deployment of STS within the healthcare organisational structure.

Furthermore, even when taking account of the genuine opportunities for such digital STS, we also need to address the many barriers to incorporating STS into the current clinical practices and regulations, for example within the UK's NHS. Therefore, in order to truly empower the communication between women who have miscarried and their formal care network, it is necessary to involve decision-makers from the NHS in the design process to address the organisational change, review the information governance regulations and policies, and to truly realise the value and need for STS support to improve the healthcare service delivery model.

8.5.2 Other Uses of Journey App

The mobile application intervention proposed in this research is designed to be used to support women who have miscarried. However, due to the flexibility of the design and its leveraging with the women's daily practice, the designed technology also has the potential to be used widely for other early pregnancy complications, such as Ectopic pregnancy or Molar pregnancy, or to educate other caregivers.

8.5.3 Improving the Miscarriage Circle of Care Model

As discussed in Chapter 3, both care networks, formal and informal, play an essential role in providing a specific type of social support owing to the difference of miscarriage experiences and the different reactions of women. Thus, when designing technology to support women in the miscarriage context, it is important to consider the need to empower those care networks with the tools that facilitate coordination and collaboration with their informal and formal care networks, and to integrate access to these

resources explicitly in the MCCM.

However, as we found in Chapters 3 and 4, communication challenges evolve beyond the interaction of women and their formal and informal care network. This includes inter-network communication and dissemination of information, which is not widely acknowledged in the design for miscarriage services, and requires careful consideration of confidentiality when sharing potentially sensitive information. Enhanced care network roles and skills will result in continuous adaptation of the MCCM that promotes communication of the care networks.

There is also a crucial need to promote continuous care and engagement of the society with regard to understanding miscarriage circumstances beyond mobile education and training. Thus, the design of *Journey* app might introduce various models of communication (including synchronous or asynchronous communication) that can be used in the models of contact for different care configurations (including peer-to-peer, women-to-informal care network, and Peer Advisor-to-formal care network). Further research would be necessary into this area, but is beyond the scope of this thesis.

8.6 Summary of Contributions

The thesis has introduced three main contributions.

Firstly, the research has contributed with an in-depth and rich holistic contextual understanding to an under-investigated and under-represented area of information system design known as STS, with applying HCI perspective to facilitating social support for women who have miscarried, describing in depth their practices and use of technology.

Secondly, the thesis further contributes to extending the circles of care approach. Here, we have introduced the design implications of MCCM to enable communication, peer advisor collaboration, highlight the importance of integrating the Peer Advisor support to provide holistic support for the woman experiencing a miscarriage.

Thirdly, this research has ultimately contributes in proposing an empirical design goals for miscarriage care STS that are grounded with women from different cultures and different health care systems.

8.7 Conclusion

Our study has hence been motivated by the impact of socio-technical intervention in improving the communication between women who have miscarried and their formal and informal care networks, encouraging women to reach out for their appropriate social support, which was challenging to gain owing to the lack of knowledge and stigma surrounded the topic of miscarriage. Therefore, a multi-pronged quantitative and qualitative piece of research has been conducted to explore this area further and to understand, design, evaluate and review. Four studies have been conducted through design engagement with women who have miscarried and consultation occurred with the Miscarriage Association as a relevant charity organisation. We also have been fortunate to engage people who have not experienced miscarriage in the study, as presented in Chapter 5.

Our findings have added substantially to our understanding of the issues surrounding miscarriage service and the deliverance of appropriate social support, as well as the women's communication of their needs in terms of informational, emotional, esteem and network support. In this research, we have thus recognised the need to empower the Peer Advisors' expertise and their central role within the miscarriage circle of care, while addressing surrounding issues of coordination and communication with the formal care network and members of the wider informal care network. In addition, this thesis set out to investigate design requirements and strategies and STS to promote the MCCM adoption in the existing practice of women who have experienced miscarriage, and augment their communicating with their formal and informal care networks.

Our exploration, understanding, and design process for STS have revealed a number of opportunities to identify the potential for the sensitive design of digital platforms with the objective of improving the social support services provided to women who are experiencing or have experienced miscarriage. Ultimately, we found that this STS addresses a holistic approach that is loosely coupled with the specific structure of a miscarriage circle of care and is more focused on facilitating womens' social support needs and communication with their care networks. Through reflection on the studies conducted in this research, it has been possible to:

- create a design concept for a STS to support women who have miscarried, one resulting in a new formal network-integrated relational healthcare model; and
- inform the methodological engagement process through which the role of design

and power relations with the community are investigated and where we, as informational system researchers, must ensure reconfiguration of sustainable and adoptable digital solutions.



Ethics Approvals

In this thesis, the study described in studies in Chapter 3 were approved by Indiana University's Institutional Review Board and University of Edinburgh's Psychology Research Committee. The studies described in Chapters 4, 5, and 7 were approved by University of Edinburgh's Psychology Research Committee. This appendix includes the approval notices for these studies.

KC IRB
Protocol #: 1709149336
Investigator: Siek, Katie A.
Summary Printed 01/08/2018

IRB APPROVAL

This research project, including all noted attachments, has been reviewed and approved by the Indiana University IRB.

☐ Exempt Category(ies), if applicable:

☒ Expedited Category(ies), if applicable: (7)

Study meets the criteria of approval for a period of: ☐ one (1) year ☒ two (2) years ☐ other, _____

Reviewing IRB Committee: IRB-IUB
Level of Review: Expedited

Authorized IRB Signature: John M Kennedy Digitally signed by John M Kennedy
DN: cn=John M Kennedy, email=jmk22@outlook.com, c=US
Date: 2018.01.08 19:36:09 -05'00' IRB Approval Date: _____

Printed Name of IRB Member: _____



PPLS RESEARCH ETHICS COMMITTEE
SCHOOL of PHILOSOPHY, PSYCHOLOGY and LANGUAGE SCIENCES
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10 September 2019

Ethics proposal 298-1819/7, entitled Together for Change: Towards eHealth Tools for Supporting Miscarriage and submitted by Maria Wolters, Professor Helen Pain and Mona Alqassim has been approved by the PPLS Research Ethics Committee per the Department's ethics regulations.

B

PIS and CF for ARC Study and Co-design Workshops

In this thesis, before starting the ARC study described in Chapter 3 and the co-design workshops described in Chapters 4 and 7, we provide PIS and asked participants to consent the form. This appendix includes the PIS and CF for those studies.

IRB Study 1709149336
Psychology Ethics Approval 209-1718/1



THE UNIVERSITY
of EDINBURGH



Towards technology that can support women who experience miscarriage

Understanding Miscarriage Support through Social Media Focus Groups

We are a team of eight researchers, two from the University of Edinburgh, United Kingdom, and six Indiana University, Bloomington, Indiana, United States. We are designing a technology that can support women who experience miscarriage. We would like to invite you to participate in a research study to design a social support platform for miscarriage support. You were selected as a possible subject because you responded to the posting about the study in the social media and you met both of the inclusion criteria below:

1. You have experienced a miscarriage
2. You are 18 years or older
3. You reside in the United States or United Kingdom

We ask that you read this form and ask any questions you may have before agreeing to be in the study. The study is being conducted by the following investigators:

Katie A. Siek, Ph.D., Professor in School of Informatics and Computing at Indiana University
Maria Wolters, Ph.D., Reader (Associate Professor) in Design Informatics at the University of Edinburgh

Lucia Guerra-Reyes, Ph.D., Professor in School of Public Health at Indiana University
James Clawson, Ph.D., Professor in School of Informatics and Computing at Indiana University
Haley MacLeod, Ph.D. student in the School of Informatics and Computing at Indiana University

Mona Alqassim, Ph.D. student in School of Informatics at the University of Edinburgh
Cassie Kresnye, Ph.D. student in School of Informatics and Computing at Indiana University
Vanessa Pereira, B.S. student in School of Informatics and Computing at Indiana University

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What is this study about?

Many people rely on technology to communicate with others who have similar experiences, and to get information about their health and wellbeing. We want to know more about the ways in which women who experience miscarriage use technology, so that we can design tech-based support tools that complement other sources of support. There are 4 main goals of this study:

- 1) Identify people in the care network of women who have had miscarriages and their roles and interactions.
- 2) Identify women who have had miscarriages experiences related to socio-technical systems.
- 3) Identify the timeline and information needs of women who have had miscarriages.
- 4.) Compare and contrast the healthcare experiences of women in the UK and US.

What does the study involve?

If you agree to be in the study, you will be invited to join a Facebook group (of 60 participants) where we will ask you to participate in activities or conversations to help inform this design process. You will be asked to answer survey questions regarding your personal information and people in your lives who provide you help and support the miscarriage. This can involve writing about your own experiences, drawing, or filling out questionnaires. You will be expected to engage in discussions, respond to prompts, or complete an activity once or twice a week. You may choose the extent to which you participate. We anticipate that this group will be active for research purposes for 8 weeks.

What are the benefits?

Through the activities, you may be able to connect with other women who have similar experiences to yours. These connections may offer suggestions and support. However, please bear in mind that this is not a support group. You will also be contributing to understand the social support system for others who experienced miscarriages and thus help design an interactive social platform for them.

What are the risks?

While in the study, the risks are:

1. Emotional distress from discussing sensitive topics
2. Possible loss of confidentiality
3. Being hurt by insensitive comments

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In order to minimize these risks, you may choose the extent to which you participate in the discussions in the Facebook group. You may discontinue the study at any time. If you experience any emotional distress, we can provide you with information about available counselling services you may contact at your discretion. We also will have an experienced team of Facebook users who will moderate the group (Cassie Kresnye and Maria Wolters)

In order to protect your privacy, we will not reveal any names or directly identifying information from your contributions in the Facebook group. You may choose to allow the use of quotations from your contributions in the group in publications or presentations of this work. You will be given a copy of any written work prior to submission for publication. We encourage you to review Facebook's terms of use before beginning the study.

How will my data be used?

We will analyze the results of all activities to determine what support needs technology could address, and to gather ideas about how to design such technology. The data will be stored on password protected, secure servers in the UK and the US. Only the research team will have access to your data. We will prepare reports, presentations, and publications about the data collected while preserving your anonymity at all times.

Confidentiality

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Your identity will be held in confidence in reports in which the study may be published.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the study investigator and his/her research associates, the Indiana University Institutional Review Board or its designees, the study sponsor, and (as allowed by law) state or federal agencies, specifically the Office for Human Research Protections (OHRP), who may need to access your research records.

Confidentiality Agreement

In order to minimize risk, consent of this document includes agreeing to the following:

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Under no circumstances will I, the participant, disclose the following outside of my assigned research Facebook group:

1. Names of other participants
2. Personal Information of other participants
3. Information relating the experience of other participants
4. Other information regarding other participants (at the discretion of the participants and researchers)

By consenting to this study, I acknowledge that I have read and understood this agreement and voluntarily accept the duties and obligations to uphold this agreement.

What are my rights?

You can stop taking part in the study at any time, and you do not have to give us a reason why. We can delete all your information from the study, if you wish. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with The University of Edinburgh or Indiana University.

You may choose to allow the use of quotations or images from your contributions to the discussion in publications or presentations of this work. You will be given a copy of any written work prior to submission for publication.

Behavior Expectations in the Group Environment

To maintain a friendly and stress free environment for all participants in this Facebook group study are expected to follow the guidelines listed below.

Please do not post comments or contents that could be understood to be:

- Discriminatory
- Harassing
- Offensive
- Inappropriate
- Threatening
- Obscene
- Bullying
- Insensitive
- Demeaning

The investigators will contact anyone who violates the guideline for the first time to suggest ways to stay in the group without further violation. If the participant violates the guideline more

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than once, they will be removed from the study. Consenting to this study includes agreeing to act in accordance to these guidelines.

Payment

You will receive a gift card (or equivalent) of \$50 USD (35 GBP) for taking part in this study to be paid at the end of the study.

Contacts for questions or problems

For questions about the study, contact the researchers during regular business hours (8:00AM - 5:00PM):

(UK) Mona Alqassim at +131-651-1768 or by email at m.y.m.alqassim@sms.ed.ac.uk

(US) Cassie Kresnye at +440 -725-4126 or by email at ckresnye@iu.edu

For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact Helen Pain +44 (0) 131 650 8485 (for UK) or the IU Human Subjects Office at (812) 856-4242 (for US)

Participant Consent

Please send an email to m.y.m.alqassim@sms.ed.ac.uk or ckresnye@iu.edu indicating your decision to consent or not to consent to participate in the study.

1. "I _____ (your name) got the copy of the informed consent, after consideration of all the information provided in it, I give my consent to participate in this research study on _____ (date)."

2. "I _____ (your name) got the copy of the informed consent, after consideration of all the information provided in it, I do not give my consent to participate in this research study on _____ (date)."



Participant Information Sheet

Together for Change: Towards eHealth Tools for Supporting Miscarriage

You are invited to take part in a research study. To help you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

We are a team of three researchers: Mrs Mona Alqassim, PhD student at the School of Informatics, University of Edinburgh, and her supervisors, Dr Maria Wolters and Prof Helen Pain.

In our research, we want to design solutions for supporting women who are experiencing or have experienced a miscarriage. In particular, we are interested in meaningful ways to use technology (apps, social media, etc.) to do so. This co-design workshop is part of that process. We want to figure out, together with you, what kinds of social support and what services should be included, what technology should be used (existing apps or social media services, new tools, online forums, etc.), and how the solutions should be designed.

Why have I been invited to take part?

You have been asked to take part because you have experienced at least one miscarriage, and have indicated that you might be interested in our study when we reached out to you either on the Facebook groups of the previous study in which you were involved, through one of our charity partners, or through a leaflet.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen if I take part?

If you agree to be in the study, a researcher will take you through a one-on-one co-design workshop, which consists of a series of interactive activities that are designed to help us understand what support around miscarriage people access, how they access it, and to whom they turn for support. We will use a variety of techniques, which may include sharing your experiences of what has and has not worked for you in the past; sorting concepts into groups; commenting on prototypes that others have designed or suggesting your own designs. The researcher will be experienced in working on sensitive topics, and there will also be a note-taker. You are free to take a break from the workshop at any time; we will provide a safe and welcoming space where you can do so.

We would like to audio record the workshop, and video record only the materials on the table during the workshop, and take photos of any feedback, post its, designs, or other artefacts that you produce. However, we will not do so if you feel uncomfortable with it.

The workshops will take at most two hours. We will compensate you for your time with a £20 One4All voucher, but unfortunately, we do not have the funds to pay for child care.

We will analyse the results of all activities to determine how could address the support needs of women who have miscarried, and to gather ideas about how to design such technology.

In order to protect your privacy, we will not reveal any names or directly identifying information from your contributions in the workshop. You may choose to allow the use of quotations in publications or presentations of this work. We will also anonymise all notes, drawings, and paper prototypes that you agree to leave with us after the workshop.

Should you agree to be audio recorded, the resulting audio data will be transcribed by a GDPR compliant transcription service and fully anonymised by the researcher with assistance from her supervisors. Should you agree to being video recorded, the resulting video data will be annotated. Any photos that you allow the researchers to take will be annotated and, if they contain text, transcribed. Any identifying information will be anonymised.

What are the possible benefits of taking part?

There are no direct benefits to you taking part in this study, but the results from this study might help to improve the healthcare of patients in the future.

The results of this study may be used for the future development of a new app or platform. While your participation in this study will not entitle you to benefit financially from this, we will aim to ensure that the developer is a non-profit, community oriented business.

What are the possible disadvantages of taking part?

While in the workshop, the risks are:

- Emotional distress from discussing sensitive topics
- Being hurt by insensitive comments

You are completely free to choose the extent to which you participate in the workshop. You can leave the workshop or take a break from the discussion at any time, and choose to stop and skip any activity that makes you feel uncomfortable. We will provide a quiet room for those who wish to take breaks. While we will do everything we can to minimise distress, you may also experience unexpected strong emotions as a result of the discussions.

Here are some relevant sources of support:

Miscarriage Association:

<https://www.miscarriageassociation.org.uk>, Helpline 01924 200 799,
info@miscarriageassociation.org.uk

SANDS Stillbirth and Neonatal Death Charity:

<https://www.sands.org.uk>, Helpline 0808 164 3332
helpline@sands.org.uk

For further links, see <https://copingwithpregnancyloss.com/support/>

What if there are any problems?

If you have a concern about any aspect of this study please contact Prof Helen Pain helen.pain@ed.ac.uk who will do their best to answer your questions.

What will happen if I don't want to carry on with the study?

You can stop taking part in the workshop at any time, and you do not have to give us a reason why. We can delete all your information from the study, if you wish. Leaving the workshop will not result in any penalty or loss of benefits to which you are entitled.

Your decision whether or not to participate in this study will not affect your current or future relations with The University of Edinburgh. Once you withdraw from the study, your data will not be used in any further publications and for any further research.

What happens when the study is finished?

After the end of the data collection, we will keep any research notes, transcripts, annotations, and photos for at least five years to ensure that we have enough time to analyse it, and to write it up for publication.

Will my taking part be kept confidential?

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage. The data will be stored on password protected, secure servers in the UK or on password-protected, encrypted research laptops. Only the research team will have access to your data. You may choose to allow the use of quotes or images from your contributions to the discussion in publications or presentations of this work. We will prepare reports, presentations, and publications about the data collected while preserving your anonymity at all times.

What will happen to the results of the study?

This study will be written up in Mrs Alqassim's PhD thesis, and submitted to academic journals and conferences. We will also share our findings with charities.

You will not be identifiable from any published results.

We will inform you of any publications through the study web page <https://blogs.ed.ac.uk/mona-alqassim/>

Who is organising and funding the research?

The study is being funded by the Alan Turing Institute Seed Funding Grant "Generating Health Data" to Dr Maria Wolters and a PhD scholarship awarded by the Saudi Arabian Government to Mrs Mona Alqassim.

Who has reviewed the study?

Ethics certification documents for this study, including the participant information sheet and consent form, have been reviewed by the Informatics Ethics Panel of the University of Edinburgh, and the document have been certified as complete and correct (298-1819/7).

This study builds on the results of an earlier study conducted on Facebook, which can be accessed here: <<https://blogs.ed.ac.uk/mona-alcassim/arc-study/>>

Sponsorship has been obtained.

Researcher Contact Details

If you have any further questions about the study please contact Mrs Mona Alqassim at 0131 651 1768 (weekdays, 9am-5pm) or by email at mona.alqassim@ed.ac.uk.

Independent Contact Details

If you would like to discuss this study with someone independent of the study please contact Dr Robin Hill, r.j.hill@ed.ac.uk.

Complaints

If you wish to make a complaint about the study please contact the Informatics Research Ethics Panel at <inf-ethics@inf.ed.ac.uk>

CONSENT FORM

Together for Change: Towards e-health Tool for Supporting Miscarriage

Please initial box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these questions answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my medical care and/or legal rights being affected. ☐
3. I understand that data collected about me during the study may be converted to anonymised data. ☐
4. I agree to the workshop being audio recorded. Yes ☐ No ☐
5. I agree to the workshop being video recorded. Yes ☐ No ☐
6. I agree to having pictures taken of any artefacts that I produce. Yes ☐ No ☐
7. I agree to my audio recorded interview being transcribed by a third-party contractor. Yes ☐ No ☐
8. I agree to take part in the above study. ☐

Name of Person Giving Consent	Date	Signature
Name of Person Receiving Consent	Date	Signature



Demographics Survey

In this thesis, in the ARC study described in Chapter 3 we distributed a demographics survey for participants to complete. This appendix includes the demographics survey for this study.

Facebook Use

How often do you log in to Facebook? *Optional*

- ☐ Daily
- ☐ 4-6 times a week
- ☐ 2-3 times a week
- ☐ Once a week
- ☐ Rarely
- ☐ Never

How often do you post on Facebook? *Optional*

- ☐ Daily
- ☐ 4-6 times a week
- ☐ 2-3 times a week
- ☐ Once a week
- ☐ Rarely
- ☐ Never

How many Facebook groups do you belong to (excluding the Facebook group for this study)? *Optional*

About Yourself - Basic

What is your age group? * *Required*

- ☐ 18-24
- ☐ 25-29
- ☐ 30-34
- ☐ 35-39
- ☐ 40-44
- ☐ 45-49
- ☐ 50 or older
- ☐ Prefer not to say

What is your gender? * *Required*

- ☐ Female
- ☐ Male
- ☐ Genderfluid/ Genderqueer
- ☐ Intersex
- ☐ Prefer not to say
- ☐ Other

If you selected Other, please specify:

Have you had a live birth after your last miscarriage? * *Required*

☐ Yes

☐ No

Country

Where do you currently live? * *Required*

- ☐ In the United Kingdom (England, Wales, Scotland, Northern Ireland)
- ☐ In the United States (including Hawaii, Alaska, and Puerto Rico)
- ☐ None of the above

About Yourself - UK Specific

What is your ethnic group?

- ☐ White (British, Irish, European, Traveller/ White Gypsy, white other)
- ☐ Asian or Asian British (Indian, Pakistani, Bangladeshi, Chinese, Asian other)
- ☐ Black or Black British (Caribbean, African, other)
- ☐ Mixed or British Mixed (White and Black Caribbean, White and Black African, White and Asian, Any other mixed background)
- ☐ Other, e.g. Arab

If you selected Other, please specify:

What is your highest level of education?

- ☐ GCSE / National/ O Levels
- ☐ A Level / Highers
- ☐ Vocational qualification
- ☐ Graduate degree
- ☐ Postgraduate qualification
- ☐ Other

If you selected Other, please specify: *Optional*

What is your employment status? Please tick all that apply.

- ☐ Employed full-time
- ☐ Employed part-time
- ☐ Self-employed
- ☐ Retired
- ☐ Homemaker
- ☐ Student
- ☐ Other

If you selected Other, please specify: *Optional*

With whom do you live at the moment? Please tick all that apply

- ☐ Alone
- ☐ Spouse or partner
- ☐ Children
- ☐ Parents
- ☐ Friends
- ☐ Flatmate
- ☐ Other

If you selected Other, please specify: *Optional*

What type of health insurance do you have? Please tick all that apply.

- ☐ NHS only
- ☐ Private insurance - dental only
- ☐ Private insurance - specialist appointments only
- ☐ Private insurance - full coverage
- ☐ Other

If you selected Other, please specify: *Optional*

How often do you see a doctor, including your GP? * *Required*

- ☐ At least once every six months
- ☐ At least once a year
- ☐ Most years
- ☐ Rarely
- ☐ Other

If you selected Other, please specify: *Optional*

About Yourself - US Specific

Which race do you most closely identify with? Please tick all that apply

- ☐ White (British, Irish, Irish, Traveller/ White Gypsy, white other)
- ☐ Asian or Asian American
- ☐ Black or African American
- ☐ Hispanic or Latino
- ☐ Native American or Alaska Native
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ Middle Eastern
- ☐ Other

If you selected Other, please specify:

What is your highest level of education?

- ☐ No high school diploma or GED
- ☐ High School Diploma
- ☐ GED
- ☐ Some College
- ☐ Trade or Vocational School
- ☐ Associate's Degree
- ☐ Bachelor's Degree
- ☐ Professional or other Terminal Degree
- ☐ Doctoral Degree
- ☐ Other

If you selected Other, please specify: *Optional*

What is your employment status? Please tick all that apply.

- ☐ Employed full-time
- ☐ Employed part-time
- ☐ Self-employed
- ☐ Retired
- ☐ Homemaker
- ☐ Student
- ☐ Other

If you selected Other, please specify: *Optional*

With whom do you live at the moment? Please tick all that apply

- ☐ Alone
- ☐ Spouse or partner
- ☐ Children
- ☐ Parents
- ☐ Friend
- ☐ Group Home
- ☐ Other

If you selected Other, please specify: *Optional*

What type of health insurance do you have? Please tick all that apply.

- ☐ Private Healthcare Insurance
- ☐ Medicaid
- ☐ CHIP (Children's Health Insurance Programme)
- ☐ I do not have health insurance
- ☐ Other

If you selected Other, please specify: *Optional*

Do you attend annual wellness appointments?

- ☐ Yes, every year
- ☐ Yes, most years
- ☐ Rarely
- ☐ No, never

If you selected Other, please specify: *Optional*

Technology Use

Which of these devices do you have and use? * *Required*

Please don't select more than 1 answer(s) per row.

Please select at least 9 answer(s).

	Don't have one	Use daily	Use weekly	Use rarely
Laptop computer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Desktop computer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Smartphone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tablet (e.g., iPad)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
eReader (e.g., Kindle)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Game console (e.g., Xbox, Nintendo DS)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Smart Watch (e.g., Samsung Gear, iWatch)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Activity Tracker (e.g., Fitbit)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other, please specify below	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you would like to tell us more about the devices you have and use, please use this space to do so.

Which social networking, messaging, and communication apps do you use? *

Required

Please don't select more than 1 answer(s) per row.

Please select at least 11 answer(s).

	Don't have one	Use daily	Use weekly	Use rarely
Twitter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Snapchat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Facebook	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Line	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
WeChat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Facebook Messenger	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
WhatsApp	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
LinkedIn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skype/Facetime/Google/Voice call	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Instant Messenger (e.g., Google Talk, Yahoo Messenger, AIM)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other, please specify below	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you would like to tell us more about the social networking, messaging, and communication apps, please use this space to do so.

About Your Wellbeing

Below are some statements about feelings and thoughts.

Please tick the one that best describes your experience of each over the last 2 weeks *

Required

Please don't select more than 1 answer(s) per row.

Please select at least 7 answer(s).

	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been feeling useful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been feeling relaxed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been dealing with problems well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been thinking clearly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been feeling close to other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been able to make up my own mind about things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Facebook ID

To reconfirm that we have the right person, please tell us your name on Facebook. *

Required



Aims and Associated Activities in ARC Study

Here is a subset of activities that we engaged the participants in during the 8-week study on the closed Facebook groups. These are activities that we built on based on participants' responses. The activities in this study are shown below. Each includes the reason for including the activity, what areas it belongs to, as well as the formal wording and documents. We posted activities on regular time each week, Monday and Thursday at 8 am US time and 1 pm UK time.

Week 1: During this time frame, people are being added to the Facebook group

Activity 1 - Meet and Greet

Aim: Icebreaker

Post to groups: 4 June 2018

“Welcome to our 8 weeks study to help us design systems to help women through miscarriage experiences. Let’s get to know each other. If you could have a superpower,

what power would it be? Feel free to respond to each other's posts and welcome everyone to the group."

Activity 2 – Facebook Availability

Aim: find a weekday and time to post that works best for the participants' schedules.

Post to groups: 7 June 2018

"We want to hear from you on what days you would like us to post-study activities through a short survey. We will post 2 activities per week." Followed by a Facebook survey of the following: What day of the week do you prefer for us to post activities? Mon, Tue, Wed, Thu, Fri, Sat

Week 2

Activity 3 - Drawn Timeline

Post to groups: 11 June 2018

[ACTIVITY] We would like to learn about your experience. You can create a timeline (like the one here from one of our researchers) or type out a timeline about your miscarriage experience. You can be as detailed as you would like. To help with this activity, think about pregnancy events you experienced if/when you sought medical help, the miscarriage symptoms/confirmation, and events that surprised you. You can post as many timelines as you would like. You also may send privately.

Activity 4 – Emotional Wellbeing Scale

Aim: This activity is designed to be administered once during the course of the study, and is used to ensure the wellbeing of the participants.

Post to groups: 14 June 2018

"[ACTIVITY]: We want to know how you are doing right now. Please fill out the following survey:" (Documentation of this survey was attached)

Week 3**Activity 5 – Dear Abby**

Aim: This activity is designed to understand the experience these participants had as well as advice from them.

Posted to Groups: 18 June 2018

[ACTIVITY] For this activity, please respond to this Dear Abby letter as if you were Abby herself. Feel free to include the resources you used:

Dear Abby, I found out last week that I had a miscarriage. I only told my partner, mom, and best friends that I was pregnant, but I still feel like I've let everyone down. I'm not sure why - everyone says it is not my fault. But I wonder what I could have done differently or what I should do now to help me through the physical and emotional issues. I have been reading online, but I'm not really sure what comes next. Any advice? Thanks, Mom2B

Activity 6: Miscarriage Experience

Aim: This activity is designed to understand each participant's experience of who was there for them.

Posted to Groups: 21 June 2018

“[ACTIVITY]: “Tell us about your experience with miscarriage. Who was there? Who was missing? What happened? If you would like to share privately, please private message“

Week 4**Activity 7 – Circle Diagram**

Aim: This activity is designed to determine who is in a participant's care network with labels of why they are placed in specific rings.

Post to groups: 25 June 2018

[ACTIVITY] For this activity, you will need a piece of paper, and a pen. Who would you want in your social support network and to turn to for help? We want to talk about

the friends, family, and others you turn to for social and emotional support. Here is an example of a woman who had a miscarriage recently where she shows on the left her social and emotional support network while she was pregnant, and to the right her support network after the miscarriage.

Activity 8 - Brief COPE

Aim: This activity is designed to determine which coping activities are used and how they learned about them.

Post to Groups: 28 June 2018

[ACTIVITY]: There are many ways to try to deal with problems. Obviously, different people deal with things in different ways, but we are interested in how you have tried to deal with your experience in miscarriage. Please check out your email, you should have received “online surveys“ email, please fill in the survey.

Week 5

Activity 9 – Social Communication

Aim: This activity is designed to determine what how participants communicate their social support need to their care network and the information a participant shares with different portions of care network.

Posted to Groups: 2 July 2018

[ACTIVITY] We want to talk a little bit more about your network in regards to miscarriage and pregnancy loss. (A) How knowledgeable are the people in your care network about your needs and your partner’s needs? (B) If you were giving information to your support group, what kind of information would you give? Who would you share it with?

Activity 10 - Social Support

Aim: This activity is designed to understand who is in a participant’s care network and whom they relied in specific social support needs.

Posted to Groups: 5 July 2018

“Think back to your network – Who do you communicate with for specific questions? Please check out your email, you should have received “ EDINBURGH“ email, please fill in the survey. In the survey, there is a list of your network. Please pick one or more support options from each question. There are some of the things you may want to communicate with people in your network.”

Week 6

Activity 11 – Coping Mechanisms

Aim: This activity is designed to understand the coping mechanisms of participants in the form of an advice column.

Post to Groups: 9 July 2018

“[ACTIVITY] What are your tips for coping? What helped you cope with your miscarriage experience?”

Activity 12 – Missing Information

Aim: This activity is designed to understand what information was missing from the participant’s experience.

Post to Groups: 12 July 2018

[ACTIVITY]: “ Let’s talk about what information you would have liked to have received after your miscarriage. Tell us what information you needed and how you would have liked to receive that information?”

Week 7

Activity 13 – Importance of Information

Aim: This activity is designed to gain insight into how important each snippet of information is for a person to know as they experience a miscarriage.

Post to groups: 16 July 2018

[ACTIVITY] Good Morning! Today we want to understand what information is important to you. You will receive an email with a link to the survey today, please message us if you do not receive it by noon. (Documentation of this survey was attached)

Activity 14 – Technology Usage

Aim: This activity is designed to understand what platforms the participants most preferred technology which used to access information and support.

Post to Groups: 19 July 2018

[ACTIVITY]: Hello everyone. We are interested to know what platforms are most preferred technology which you used to access information. Please check out your email, you should have received “EDINBURGH“ email with a link to the survey. Please message us if you do not receive.

Week 8

Activity 15 – Future Technology

Aim: This is for requirement gathering for an interactive social support system for miscarriages.

Post to groups: 25 July 2018

[ACTIVITY]: “We’ll be sending out a survey today [email from "online surveys"] about your preferences with technology. Once you have finished the survey, please let us know by commenting below any other features you would find useful that were not mentioned :)”. Please let us know if you haven’t received the survey.

Activity 16 – Goodbye

Aim: Farewells from the researchers and announcement of how the group will remain intact for non-research purposes.

Last post to the groups: 27 July 2018

[ACTIVITY]: Thank you all for sharing your experiences with the group. Our research is concluded, we will no longer be collecting any information from the group. You

may continue to participate in this group if you choose, and we encourage you to review Facebook's privacy policy for information about how your information will continue to be used should you decide to continue. In this coming week, you will receive an email from [Mona Alqassim and/or EDINBURGH] regarding a follow-up surveys. Once completed, we will submit for compensation, which will take at least one week. In December, we will post our paper draft that we will submit in January, and would appreciate the group's feedback. Thank you again, we wish the best for you all."



A8: Brief COPE Survey

Brief COPE

Page 1: Page 1

About The Ways in Which You Cope with Pregnancy Loss and Miscarriage.

This survey has two parts. In the first part, we ask you to what extent you use common strategies to cope with your experience of pregnancy loss and miscarriage.

In the second part, we would like to hear more about your own story, and how you coped with the physical and emotional adjustments after miscarriage.

Part 1: Coping Strategies Questionnaire

Below is a set of Coping Strategies. These strategies deal with ways you coped with the stress in your life when you found out you were going to lose your pregnancy.

Please do not answer on the basis of whether it seems to be working or not—just whether or not you did it or are still doing it. Try to rate each item separately from the others. Make your answers as true FOR YOU as you can.

1. I have been turning to work or other activities to take my mind off things. * Required

2. I have been concentrating my efforts on doing something about the situation I'm in.
* Required

3. I have been saying to myself "this isn't real." * Required

4. I have been using alcohol or other drugs to make myself feel better. * Required

5. I have been getting emotional support from others. * Required

6. I have been giving up trying to deal with it. * Required

7. I have been taking action to try to make the situation better. * Required

8. I have been refusing to believe that it has happened. * Required

9. I have been saying things to let my unpleasant feelings escape. * Required

10. I have been getting help and advice from other people. * Required

11. I have been using alcohol or other drugs to help me get through it. * Required

12. I have been trying to see it in a different light, to make it seem more positive. * Required

13. I have been criticizing myself. * Required

14. I have been trying to come up with a strategy about what to do. * Required

15. I have been getting comfort and understanding from someone. * Required

16. I have been giving up the attempt to cope. * Required

17. I have been looking for something good in what is happening. * Required

18. I have been making jokes about it. * Required

19. I have been doing something to think about it less, such as going to movies,

watching TV, reading, daydreaming, sleeping, or shopping. * Required

20. I have been accepting the reality of the fact that it has happened. * Required

21. I have been expressing my negative feelings. * Required

22. I have been trying to find comfort in my religion or spiritual beliefs. * Required

23. I have been trying to get advice or help from other people about what to do. * Required

24. I have been learning to live with it. * Required

25. I have been thinking hard about what steps to take. * Required

26. I have been blaming myself for things that happened. * Required

27. I have been praying or meditating. * Required

28. I have been making fun of the situation. * Required

Page 3: Thanks You

Key for selection options

1 - I have been turning to work or other activities to take my mind off things.

1 = I have not been doing this at all

2 = I have been doing this a little bit

3 = I have been doing this a medium amount

4 = I have been doing this a lot

Page 2: Page 2

Part 2: Your Story

In this section, you can tell us more about how you adjusted to life after miscarriage and pregnancy loss, if you wish.

29. How did you cope with the physical changes and adjustments, the effects that the miscarriage had on your body?

30. How did you cope with the emotions you experienced after miscarriage?



A10: Care Network Survey

Care Network

Support Network

Support Networks

In this survey, we would like to know more about the people and groups on whom you can rely for support. In the first set of questions, we would like to know more about the people you feel you can talk to about questions related to your health and wellbeing, and in the second set of questions, we would like to know more about practical help, and groups that you belong to.

Your physical health - who do you talk to? If you share information with multiple people, you could use "other" to say who those people are. * Required

If you selected Other, please specify:

Your emotional wellbeing - who do you talk to? If you share information with multiple people, you could use "other" to say who those people are. * Required

If you selected Other, please specify:

Questions about medical procedures and medications - who do you talk to? If you share information with multiple people, you could use "other" to say who those people are. * Required

If you selected Other, please specify:

Anything related to miscarriage - who do you talk to? If you share information with multiple people, you could use "other" to say who those people are. * Required

If you selected Other, please specify:

Is there anything that you would like to be able to talk about with others but don't feel comfortable doing so? Please type your thoughts below.

Other than being there to talk, what kind of practical help would you like from your care network that would help you in the immediate weeks after miscarriage? Please select all that apply. *Optional*

- | | | |
|--|---|--------------------------------------|
| <input type="checkbox"/> Laundry | <input type="checkbox"/> Cooking / Meals | <input type="checkbox"/> Cleaning |
| <input type="checkbox"/> Driving | <input type="checkbox"/> Shopping / Grocery | <input type="checkbox"/> Pet walking |
| <input type="checkbox"/> Babysitting/ child care | <input type="checkbox"/> Other | |

If you selected Other, please specify:

For each of these types of help, is there someone from your care network whom you would ask help? * *Required*

Please don't select more than 1 answer(s) per row.

Please select at least 8 answer(s).

	Yes	No
Laundry	<input type="checkbox"/>	<input type="checkbox"/>
Cooking / Meals	<input type="checkbox"/>	<input type="checkbox"/>
Cleaning	<input type="checkbox"/>	<input type="checkbox"/>
Driving	<input type="checkbox"/>	<input type="checkbox"/>
Shopping / Grocery	<input type="checkbox"/>	<input type="checkbox"/>
Pet walking	<input type="checkbox"/>	<input type="checkbox"/>
Babysitting/ child care	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>

If you answered yes for any of the types of practical help listed above, could you please tell us whom you would rely on to help with what? Please type your thoughts below.

Have you ever been involved with a group or a church, gone to a fitness class, or volunteered for a charity? * *Required*

- ☐ Yes
☐ No

Before your miscarriage, have you been involved with any of the following types of groups? If you have had multiple miscarriages, please answer this question for your most recent miscarriage. * *Required*

Please select at least 1 answer(s).

- ☐ Social group (e.g., book club)
☐ Facebook group
☐ Church / Religious group
☐ Parent group
☐ Exercise / Fitness class (e.g. Yoga)
☐ Sport (e.g. Tennis)
☐ Non-profit / Charity
☐ Online forum
☐ Other

If you selected Other, please specify:

During or after your most recent miscarriage, have you been involved with any of the following types of groups? * *Required*

Please select at least 1 answer(s).

- ☐ Social group (e.g., book club)
- ☐ Facebook group
- ☐ Church / Religious group
- ☐ Parent group
- ☐ Exercise / Fitness class (e.g. Yoga)
- ☐ Sport (e.g. Tennis)
- ☐ Non-profit / Charity
- ☐ Online forum
- ☐ Other

If you selected Other, please specify:

Key for selection options

1 - Your physical health - who do you talk to? If you share information with multiple people, you could use "other" to say who those people are.

- Partner
- Close friends - face to face
- Parents
- Siblings
- Partner's parents
- Partner's siblings
- Aunts and Uncles
- Cousins
- Other Close Relatives
- Neighbours
- Coworkers
- Colleagues
- Close friends - online
- People in religious group
- People where you volunteer
- GP / Family Physician
- Health visitor / Nurse
- Obstetrician / Specialist Consultant
- I don't have anyone to talk to about this
- Other



A14: Technology Usage Survey

Page 1: Page 1

[illegible][illegible]

3. Are there any resources that you use frequently that we have missed? If yes, please tell us below.

4. What technology do you use to access information about *pregnancy*?

	* Required			
	Most of the time	Sometimes	Rarely	Never
Own Smartphone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Own Computer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Work Computer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Public Computer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
iPad/Tablets	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kindle / eReader	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paper (Books/Leaflets)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4.a. Are there any other ways of accessing information about pregnancy that you use and that we have not mentioned? If yes, please tell us about them below.

5. What technology do you use to access information about ***miscarriage / pregnancy loss***?

	* Required			
	Most of the time	Sometimes	Rarely	Never
Own Smartphone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Own Computer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Work Computer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Public Computer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
iPad/Tablets	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kindle / eReader	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paper (Books/Leaflets)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5.a. Are there any other ways of accessing information about miscarriage / pregnancy loss that you use and that we have not mentioned? If yes, please tell us about them below.

6. Where do you normally read or hear information about ***pregnancy***?

	* Required			
	Most of the time	Sometimes	Rarely	Never
At the doctor / midwife	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At a non-profit organisation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At home, in private	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At home, with others around	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Café	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Public Library	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
While driving, alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
While driving, with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6.a. If there is another space where you read or hear information about pregnancy that we have not listed, please tell us about it below, if you wish.

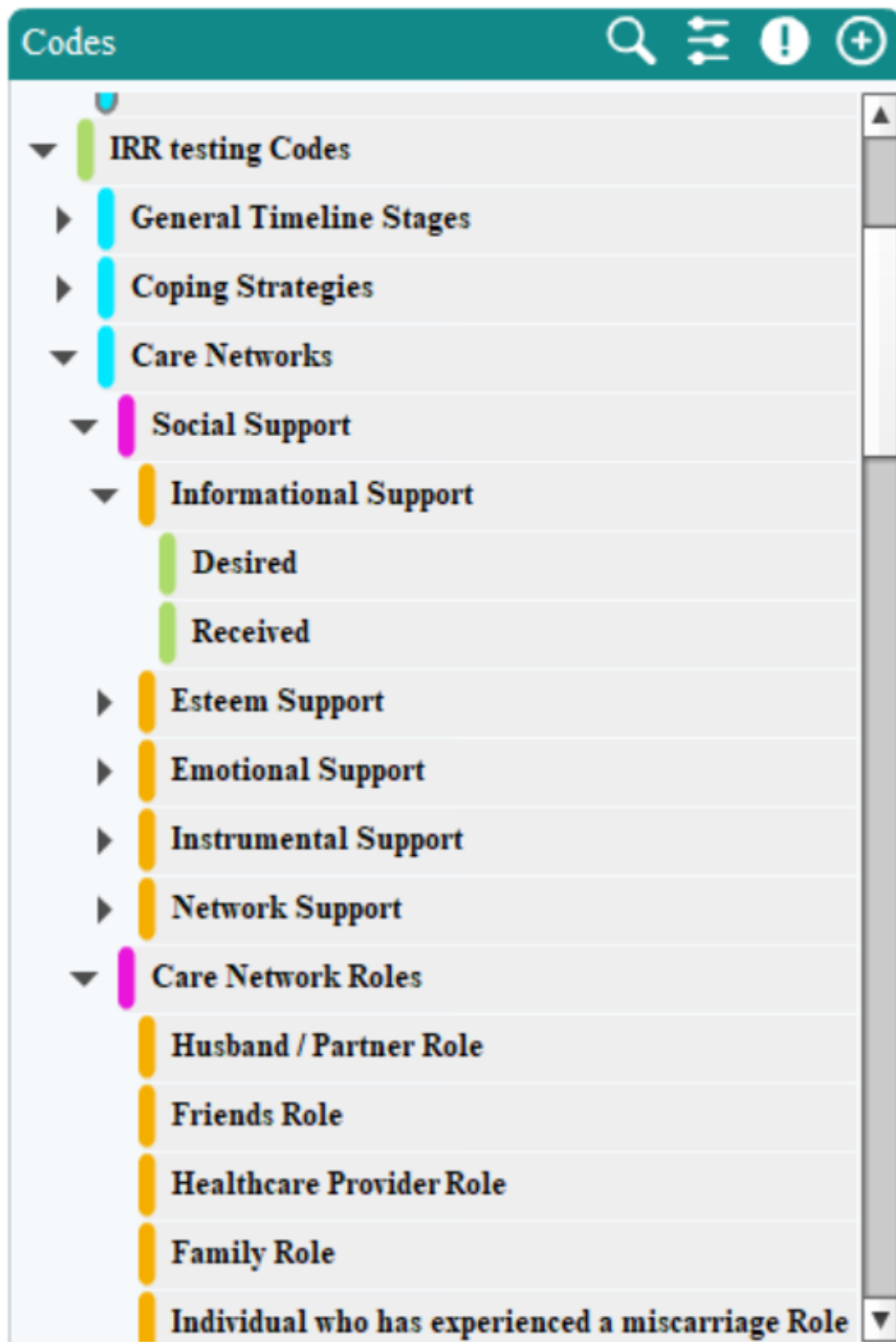
Other Social Group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Websites	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Forums	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Books	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social Media	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Videos	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>























9. Is there a trusted source that we missed? If yes, please tell us about it below.



Coding Guidelines

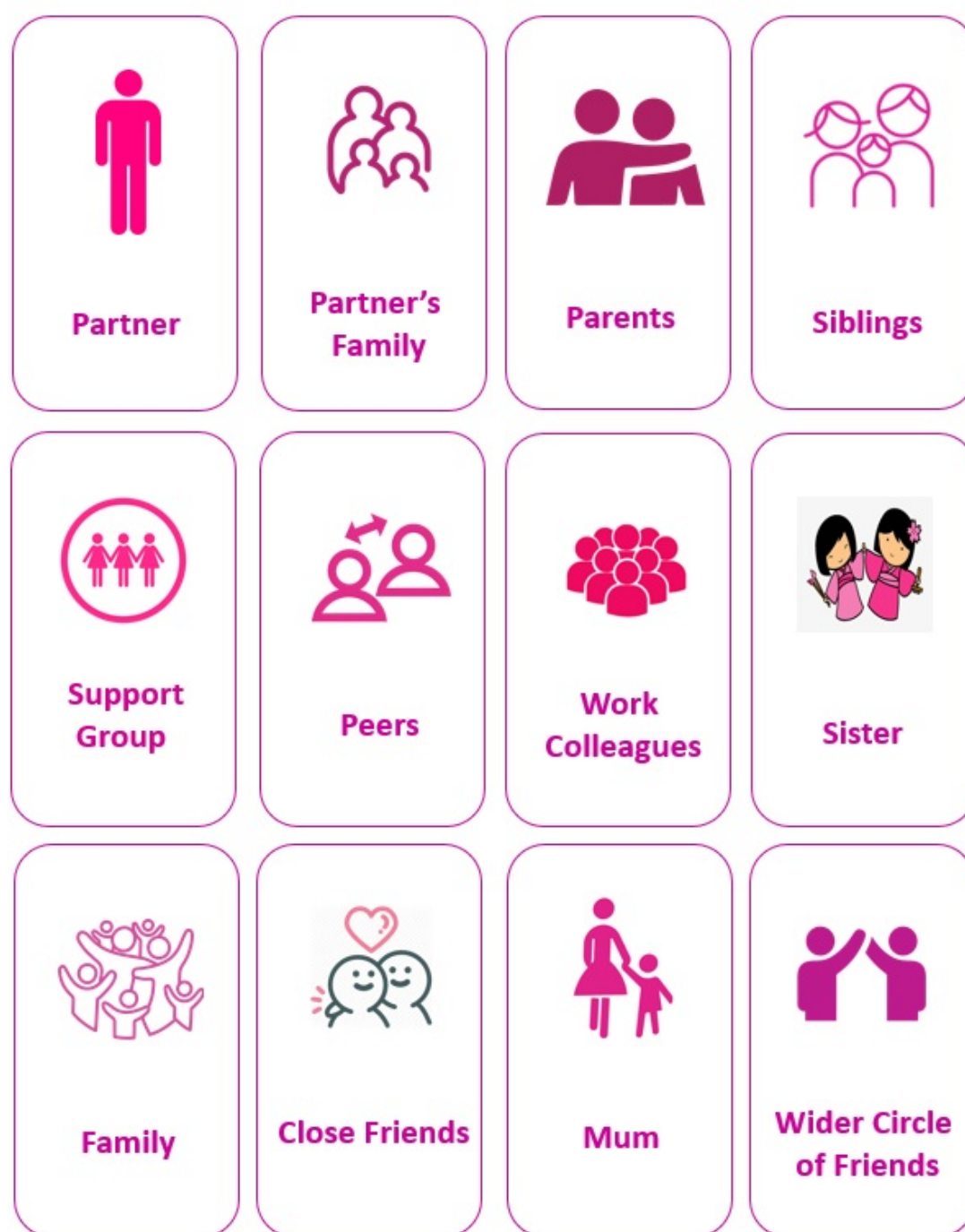
The purpose of this document is to give instructions for coding sentences for the care networks of women who have experienced miscarriage and their social support needs. We give an example of the analysis process carried out throughout this research and coding book.



Codes					
		Support Group Role			
▼		Care Network Interactions			
▼		Interaction Current			
		Interaction Difficulty with Network			
		Receiving insufficient response			
▼		Preferred Interactions			
		Breaking the taboo			
		Educating and raise awareness			
		Understand partner need			
▼		The knowledgeable of Care Network			
		In Laws			
		Family			
		Friends			
		Husband/ Partner			
		Coworkers			
		OB			
		Online Friends/ Groups			
		Therapist			



Journey Mapping Inspirational Design Cards





Midwife



Obstetrician



**Health
Visitor**



**Nurse
Practitioner**



**Other
Specialist
Consultant**



Sonographer



**General
Practitioners**



Therapist

**I want to
feel heard**

**I want
information
about
miscarriage
after- care**

**I want to
raise
awareness
and
educate
others**

**I want
information
about How
others
managed**

**I want
them to
understand
the
partner's
needs**

**I want to
discuss
feelings
and thoughts
openly,
without
judgement**

**I want
useful
suggestions
for coping
after
miscarriage**

**I want to
talk about
the
experience
of
miscarriage**

**I want
information
about the
physical
effects of
miscarriage**

**I want
information
about the
emotional
effects of
miscarriage**

**I want help
with the
grieving
process**

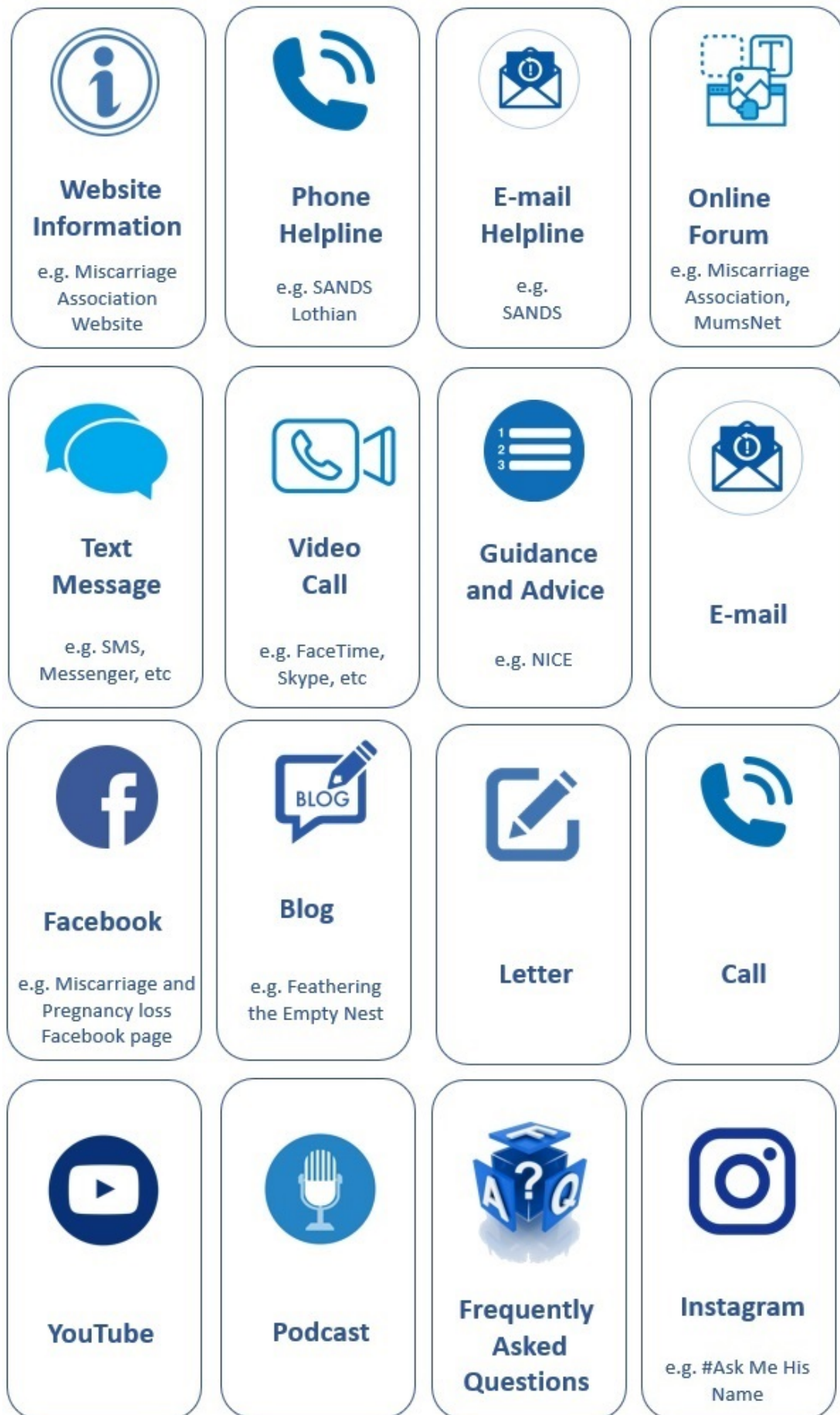
**I want help
with
travelling and
appointments**

**I want help
with chores
(Laundry,
Cooking, etc)**

**I want it to
be easier to
ask for and
coordinate
help**

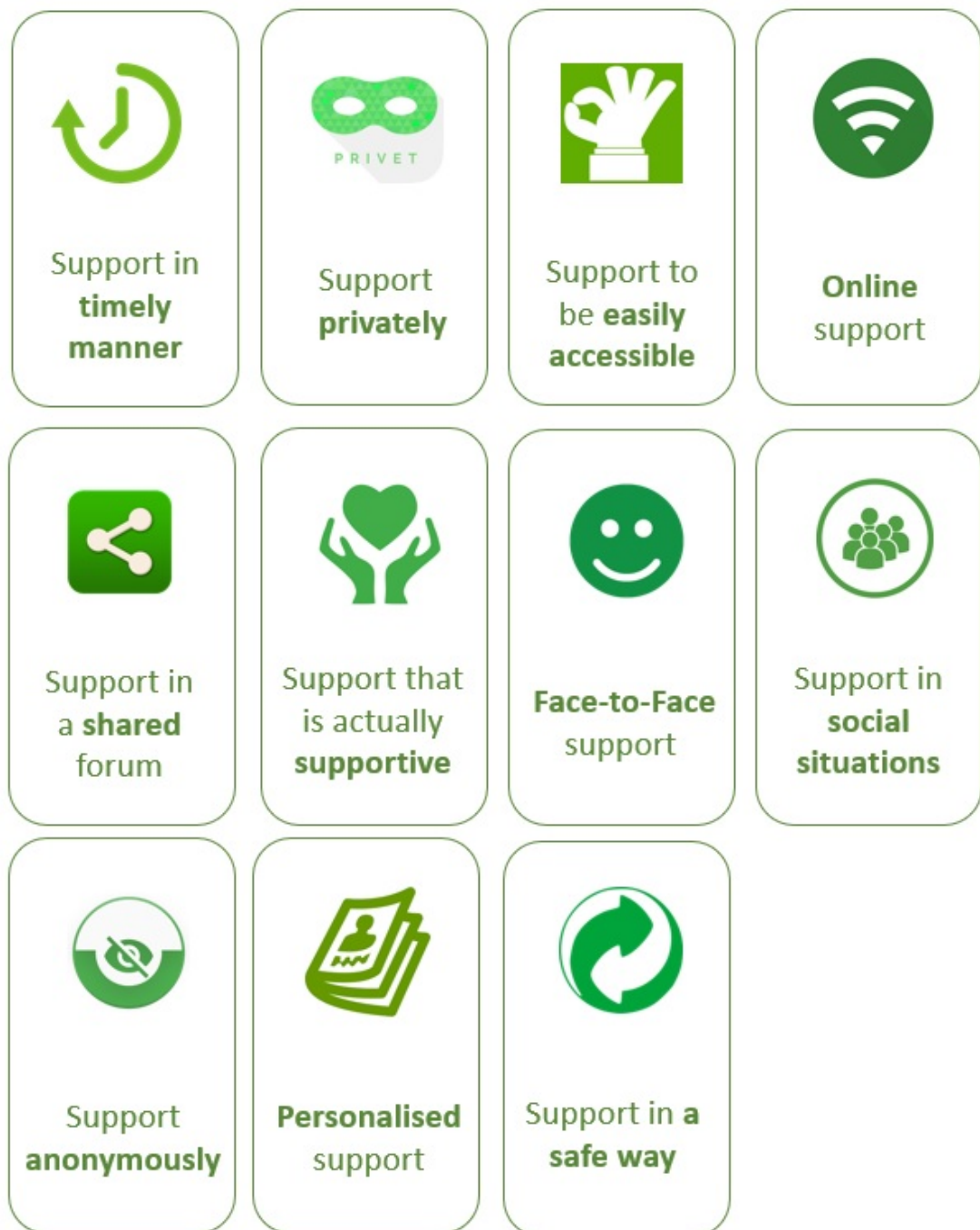
**I want help
with
childcare**

**I want help
with self-
care**



 <p>Laptop Computer</p>	 <p>Desktop Computer</p>	 <p>Smartphone</p>	 <p>Tablet (e.g., iPad)</p>
 <p>Activity Tracker</p>	 <p>Smart Watch (e.g., Samsung Gear, Apple Watch)</p>	 <p>eReader (e.g., Kindle)</p>	 <p>Game console myselforf (e.g., Xbox, Nintendo DS)</p>
 <p>Book e.g. Coping with Pregnancy Loss</p>	<p>Name Missed Technology</p> <p>Provide a description or example</p>		







Journey Mapping Questions Guide

Ice Breaker

- What activities do you usually do? (focus in particular on non-tech, outdoors, knitting)
- What is your favourite sport?
- What is your favourite food?
- How do you keep in touch with friends?

Journey Mapping

- Who are the people who are involved at each stage?
- What type of information? who form of help? and who gave both things?
- What support you had, and what other support you feel it would be helpful?
- If someone helps you, how should they help you?
- From whom do you want to receive help?

- What would you recommend to someone else from your support network to better support you?
- Is there further help for example through technology?
- Is there way from technology?
- Do you think any of these technology might have been helpful at any point?
- Would any of these technology have been used?
- Ask her about her phone, what she uses it for?
- What apps she uses?
- What she think about social media and forums?
- Whether she works with technology.
- What technology she uses?
- What she thinks in general about technology?
- If you have a magic wood, that could give you everything you need, what kind of support would you wish for?
- What tool do you think can help improve your social support needs and relationship within care network?
- what would be invented to better support your feeling and needs?
- what information do you feel that your care network could benefit from? If you could have three wishes, what would you wish it for?

Wrap-Up

- Ask her how she feels?
- Serve her tea and biscuits
- See if she needs to be comforted
- See if she needs to be distracted
- Let her talk and vent for as long as she likes
- Debrief her

- Would you mind if I send you a link during the following few days where you can provide your opinion and feedback about the workshop?

Post Survey

Workshop Evaluation

Page 1: Welcome

Thank you so much for taking part in our study "Weaving the Miscarriage Web of Care". Your participation is very appreciated. In this survey we would like to hear your opinion on the workshop. The survey should not take more than 10 minutes, and it is absolutely anonymous.

1. What did you like most about the workshop?

2. What did you like least about the workshop?

3. Did the researcher clearly explain the objectives of the workshop?

4. Did the researcher clarify any questions from you?

5. Has the workshop organized?

6. How could the workshop have been improved?

7. What activities would you like to see offered in the future?

8. Are there any other comments, ideas or suggestions you would like to share with us?

9. Are you interested to give your feedback on the workshop results?

You have completed the survey. Thank you so much :)



Online Card Sorting

This appendix contains the online card sorting instrument discussed in Chapter 5. It includes the PIS and CF, as well as questions on the characteristic of participants and their devices usage. It finally contains the post-study question that used to debrief the participants.

Welcome to Weaving the Miscarriage Web of Care Card Sorting study!

You are invited to take part in this research study which should not take longer than **30 minutes** to complete. However, to help you decide whether or not to take part, you will see detailed information about the study below, and you can confirm whether you would like to participate or not. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part.

Continue

What is the purpose of the study?

We are a team of three researchers: Mrs Mona Alqassim, PhD student at the School of Informatics, University of Edinburgh, and her supervisors Dr Maria Wolters and Prof Helen Pain.

In our research, we want to design solutions for supporting women who are experiencing or have experienced a miscarriage. In particular, we are interested in meaningful ways to use technology (apps, social media, etc.) to do so.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen if I take part?

If you agree to be in the study, you will be invited to look at situations when you would like to receive support during a miscarriage experience: Who should be giving you support, at what time, where would you like to receive support, where would you like to access support, how would you like to receive support, how would you alert the person to your needs, what support do you need? You will see cards that relate to each of these categories, and we ask you to sort them into groups that are meaningful to you.

No demographic information will be collected. The only potentially identifying information will be your Prolific Academic ID if you found this study through Prolific Academic, to ensure payment. Initially, all of your answers will be stored on password protected servers outside of the European Union run by Optimal Workshop, Ltd. After the data have been collected, they will be stored on safe, password-protected cloud servers managed by the University of Edinburgh, UK.

In order to protect your privacy, we will not reveal any names or directly identifying information from your contributions in the online card sorting. Only the team of investigators will have access to the original data set. These are Dr. Maria Wolters and Prof. Helen Pain who are academic members of staff at the University of Edinburgh and Mrs Mona Alqassim, who is a PhD candidate at the University of Edinburgh.

What are the possible benefits of taking part?

There are no direct benefits to you taking part in this study, but the results from this study might help to improve the healthcare of women who have experienced a miscarriage in the future.

The results of this study may be used for the future development of a new app or platform. While your participation in this study will not entitle you to benefit financially from this, we will aim to ensure that the developer is a non-profit, community oriented business.

What are the possible disadvantages of taking part?

When you consider the cards, you may feel emotional distress from memories evoked by some of the cards. Remember that you are completely free to choose the extent to which you participate in the online card sorting. You can stop taking part at any time and without giving a reason. Here are some relevant sources of support:

Miscarriage Association:

<https://www.miscarriageassociation.org.uk>, Helpline 01924 200 799,

info@miscarriageassociation.org.uk

SANDS Stillbirth and Neonatal Death Charity:

<https://www.sands.org.uk>, Helpline 0808 164 3332

helpline@sands.org.uk

For further links, see

<https://copingwithpregnancyloss.com/support/>

What will happen if I don't want to carry on with the study?

You can stop taking part in the card sorting at any time, and you do not have to give us a reason why. We will delete all your information from the study, if you wish. Your decision whether or not to participate in this study will not affect your current or future relations with The University of Edinburgh. Once you withdraw from the study, your data will not be used in any further publications and for any further research.

What happens when the study is finished?

After the end of the data collection, we will keep the card sorts that you have created for at least five years to ensure that we have enough time to analyse it, and to write it up for publication.

Will my taking part be kept confidential?

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage. While your original card sorting data will be stored on a server in the US, where Optimal Workshop is registered, afterwards, all data will be stored on password protected, secure servers in the UK or on password-protected, encrypted research laptops. Only the research team will have access to your data. We will prepare reports, presentations, and publications about the data collected while preserving your anonymity at all times.

What will happen to the results of the study?

This study will be written up in Mrs Alqassim's PhD thesis, and submitted to academic journals and conferences. We will also share our findings with charities.

You will not be identifiable from any published results.

We will inform you of any publications through the study web page <https://blogs.ed.ac.uk/mona-alqassim/>

Who is organising and funding the research?

The study is being funded by the Alan Turing Institute Seed Funding Grant “Generating Health Data” to Dr Maria Wolters and a PhD scholarship awarded by the Saudi Arabian Government to Mrs Mona Alqassim.

Who has reviewed the study?

Ethics certification documents for this study, including the participant information sheet and consent form, have been reviewed by the Informatics Ethics Panel of the University of Edinburgh, and the document have been certified as complete and correct (298-1819/7).

This study builds on the results of an earlier study conducted on Facebook, which can be accessed here:

<https://blogs.ed.ac.uk/mona-alqassim/arc-study/>

Researcher Contact Details

If you have any further questions about the study please contact Mrs Mona Alqassim at 0131 651 1768 (weekdays, 9am-5pm) or by email at mona.alqassim@ed.ac.uk.

Independent Contact Details

If you would like to discuss this study with someone independent of the study please contact Dr Robin Hill, r.l.hill@ed.ac.uk

Complaints

If you wish to make a complaint about the study please contact the Psychology Research Ethics Committee at psych-ethics@ed.ac.uk

- ☐ I have read the information and agree to take part in the study
- ☐ I have read the information and do not wish to take part in the study

← Back

Continue

Thank you very much for your interest in our study.

In this survey, we ask you a few questions about your miscarriage experience and your technology use which will help us analyse the information you will give us.

Optional

What is your experience with miscarriage?

- ☐ I have experienced one or more miscarriages
- ☐ My partner has experienced one or more miscarriages
- ☐ A friend or close colleague has experienced one or more miscarriages
- ☐ I am pregnant, and thinking about what would happen in case of a miscarriage
- ☐ Other

Optional

Do you have any children?

- ☐ Yes, and I have never experienced a miscarriage
- ☐ Yes, and I had a live birth after my last miscarriage
- ☐ Yes, and I had no live birth after my last miscarriage
- ☐ No, and I had no live birth after my last miscarriage
- ☐ No, and I have never experienced a miscarriage

Which of these devices do you have and use?

Laptop computer

Use daily
Use weekly
Use rarely
Don't have one

Desktop computer

Optional

Smartphone

Optional

Tablet (e.g., iPad)

Optional

eReader (e.g., Kindle)

Optional

Smart Watch (e.g., Samsung Gear, iWatch)

Optional

Activity Tracker (e.g., Fitbit)

Thank you so much for your help!

Optional

Is there anything else you would like to share with us?

(Please avoid details that could identify you.)

Submit

End of study and payment

Your response will help us design solutions that make it easy for people who have miscarried to access the support they need.

In order to receive your payment, please click on the [Prolific Academic completion link](#) if you found this study via Prolific Academic, or email Mona Alqassim (mona.alqassim@ed.ac.uk) with the study code HV3D2TMJ.



Formative Evaluation Questions Guide

Reflective Discussion

- What was your overall impression of the App?
- How did you find the experience of using this App to complete these tasks?
- What was the best/worst thing about this App?
- How could this App be improved?
- How would you compare this App to other ways to support miscarriage?

Semi-structured Interview

- Have you used a similar App for miscarriage purpose before?
- What would make you decide to use this App to reach out to your network? If not, why not?
- Can you tell me what you think of having access to online community through this App? What did you think of if the App allows you to conduct a live chat

with your midwife, and take a photo and send it to her remotely?

- What do you think if the App allows you to connect with the therapist to discuss her feelings and thoughts?
- What did you think of the App content?
- Do you suggest any other feature that could be implemented in this App to better support miscarriage experience?
- If something like this app had been available when you were pregnant, would you have used it?
- Would you recommend such an app to friends who are pregnant, or who are trying to conceive?

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